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Title

What are the needs and preferences of patients and family members discharged from the emergency department within 24 hours? A qualitative study towards a family-centred approach

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Emergency department, care planning, family, nursing, participatory design, qualitative research

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Abstract

Objective: There is an increase in patients being discharged after short stays in the emergency department, but there is limited knowledge of their perspectives on treatment and care. This study aims to explore and understand the needs and preferences of patients and family members discharged from the emergency department within 24 hours of admission.

Design: This was a qualitative study incorporating an inductive thematic analysis applied to identify key themes from field observations and interviews with patients and family members.

Setting: This study was conducted in two large emergency departments in the Region of Southern Denmark.

Participants: All adults aged ≥18 years who had been discharged from the emergency department within 24 hours were eligible to take part. Purposeful maximum variation sampling was used to recruit patients and family members with different sociodemographic features.

Results: Field observational studies (n=50 hours), individual interviews with patients (N=19) and family members (N=3), and joint interviews with patients and family members (N=4) were carried out. Four themes were derived from the material: 1) being in a vulnerable place—emotional concerns; 2) person-centred information; 3) the atmosphere in the emergency department; and 4) implications of family presence.

Conclusion: This study demonstrates a gap between patients' and family members' needs and what current emergency departments deliver. The findings highlight the importance of family and person-centred care. Tailored communication and information with genuine involvement of family members is found to be essential for enabling an understanding of the vulnerability patients and family members experience during acute illness.

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Strengths and limitations

o The findings and methodological approaches in the study have been critically evaluated and discussed by experienced researchers from different fields of research.

o Data were generated using different methods and involved a broad representation of participants to ensure robust findings.

o Quotations support the trustworthiness of the findings.

o Although there is a thorough description of the research process to support credibility, descriptions of the findings are contextual and reflect a Danish context.

Introduction

Internationally, many countries comparable to Denmark, such as the United Kingdom and Australia, work to establish an organisational structure in emergency departments (ED) to prevent overcrowding and access blockage [1]. A four-hour rule was introduced in EDs for practitioners to develop a plan of treatment: either admission or discharge was expected within four hours [1]. Across 21 Danish EDs, this same structure exists to promote clinical assessment and treatment of patients within four hours [2]. However, a lack of thoroughness in the delivery of information and assessment of patients' and family members' individual needs may result in patients being discharged from the ED who are unable to maintain their health status [3, 4]. The environment in EDs is challenging, with a diversity of health needs to be met [5]. Patient-reported outcomes were explored across two studies, and four outcomes were identified: an understanding of one's condition, symptom relief, reassurance and a treatment plan [6, 7]. Both studies targeted patient-reported measures to improve acute care but did not include the family perspective [6, 7]. Interventions related to patient outcomes are limited or focus on reducing re-admission rather than satisfying needs and preferences [8].

Globally, many initiatives focus on out-of-hospital care, such as hospital at home, telehealth and outpatient clinics [9, 10]. Therefore, family members play an active role in maintaining patient outcomes after early discharge to homes [11, 12]. Mackie et al. found in a qualitative study that health professionals identified the advantage of family participation in care for enhancing the quality of care and improving patient

satisfaction [13, 14]. However, research on the needs of family members involved in short visits to EDs is sparse or focuses on elderly patients [15, 16]. To date, little is known of how patients and families experience short-term stays in the ED and what needs and preferences they have [17, 18]. In the interest of organising and practicing tailored care, it is essential to explore the needs and preferences of patients and their family members to ensure that the care provided is valuable.

Objective

This study aims to explore and understand the needs and preferences of patients and family members discharged from the ED within 24 hours of admission.

Methods

Study design

A participatory design [19] was used to understand the experience of a short stay in the ED. This study is the first phase of a three-phase project [20]. Guided by the principles of phenomenological inquiry, field observations and interviews with patients and family members were used to investigate and understand a phenomenon within the specific field [21]. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups were used as guidelines[22].

Patient involvement

Patients and family members participated in the early phase of the overall study. As a key element, the study was built around user involvement. The qualitative approach ensured that patients' and family members' perspectives were explored in depth.

Setting

The study was conducted in EDs at two hospitals in the Region of Southern Denmark: 1) Odense University Hospital (OUH), a 1,000-bed university hospital that covers all specialties. The ED has 69,000 annual attendees. On average, 32 patients are admitted per day, and 50% are discharged within 24 hours.

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2) The Department of Emergency Medicine, Hospital of Lillebaelt, Kolding. The Hospital of Kolding has 320 beds. The ED has 50,000 annual attendees and receives 146 patients per day.

Participants and recruitment

Eligible patients and their family members were purposively recruited between August 9th and October 29th, 2020 by the first author (CØ). Initially, the nurses who provided care for each patient asked the patient's permission for CØ to approach the patient. Field observations were carried out if the patients accepted. Visitor restrictions due to Covid-19 were in place, and only one family member was allowed in the ED.

CØ asked for consent to contact the patient and/or the family member by telephone for an interview within the first week after discharge. Interviews were performed two to seven days after discharge. Interviews were conducted as face-to-face, telephone, individual or joint interviews according to participant preference and to accommodate the Covid-19 induced restrictions.

Eligibility criteria: Patients were Danish-speaking individuals ≥ 18 years old with a medical or surgical diagnosis who had been discharged from the ED after less than 24 hours. Family members accepted by the patient were included.

Exclusion criteria: Patients with cognitive impairment as evaluated by an individual clinical judgement according to their ability to comprehend the terms of participating were excluded. Highest and lowest triage level to Danish Emergency Process Triage were excluded [23].

Sample size: A target minimum sample was 20 patients, but data collection continued until thematic saturation—i.e., the point at which no new themes emerged in the analysis—was reached [24].

Patient characteristics	N (%)
Gender	
Male	9 (37.5)
Female	15 (62.5)
Age	
1 –35	3 (12.5)
36–49	5 (20.8)
50–65	5 (20.8)
66–80	6 (25.0)
81 or older	5 (20.8)
Living situation	
Living alone	11 (45.8)
Living with others	13 (54.2)
Nationalities represented in the study	4 (100)
Education level	
Below secondary school	11 (45.8)
Above secondary school	13 (54.2)
Function level	
Receives primary homecare	9 (37.5)
No help needed	15 (62.5)
Method of admittance	
By ambulance	15 (62.5)
Attending the ED alone	5 (20.8)
Attending the ED with family members	4 (16.7)
Family in the ED	
Yes	13 (54.2)
No	11 (45.8)
Frequency of stay	
First time in ED	9 (37.5)
More than one visit in the ED	15 (62.5)
Main symptoms	
Medical	10 (41.7)
Surgical	6 (25.0)
Neurological	3 (12.5)
Orthopedic	4. (16.7)
Gynecological	1. (4.2)
Co-morbidity	
Yes	13 (54.2)
No	11 (45.8)

Table 1: Characteristics of participating patients in a Danish study on needs and preferences of patients and family members discharged from the emergency department within 24 hours

Family member characteristics	(N%)
Gender *Male* *Female*	 4 3
Mean age (years)	55
Family relation to patient *Daughter* *Son* *Spouse* *Parent*	 1 1 4 1
Education level *Below secondary school* *Above secondary school*	 3 4

Table 2: Characteristics of participating family members in a Danish study on needs and preferences of patients and family members discharged from the emergency department within 24 hours

Data collection

Data collection was carried out by CØ, who has thirteen years of experience in nursing and holds a Master of Science in Nursing. She had no care responsibilities for any of the patients admitted to the ED.

Researcher characteristics and reflexivity

A phenomenological-hermeneutical approach made it possible to combine an open-minded descriptive comprehension with hermeneutic interpretation [21]. As CØ has a background as experienced nurse and qualitative researcher it was impossible not to influence the research [25]. CØ wrote down her preunderstanding a priori containing of perceptions of patients lack information being discharged and might have many concerns.

Field observational studies

By using field observation, the authors were able to directly obtain knowledge about how participants experienced the ED, as opposed to what we think is the case [21]. Moreover, it provided the opportunity to conduct ethnographic interviews, posing open questions to patients and family members to validate the author's understanding of the situation. Inspired by Spradley's nine dimensions, [26] an observational guide was designed and

pilot-tested in two cases. CØ was present at the EDs for three to six hours per day, during both morning and evening shifts, and made observations in medical and surgical areas. Field notes were written each day containing observations and quotes.

Interviews

To gain an understanding of the needs and preferences expressed, the observations were supplemented with interviews. Both individual and joint interviews were utilised, as the study aimed to explore both the perspectives of the patients and family members. Interviewing family members together has several advantages, e.g., it might create possibilities for both parties to gain a broader understanding of each other's perspectives [27]. All interviews were conducted using an interview guide inspired by Kvale and Brinkmann [25], recorded and transcribed. The guide was developed based on the identified scientific literature on the topic and the preliminary results of field observations. The interview guide was pilot tested in two cases.

Analysis

The analysis was performed according to systematic text condensation [28]. An overall caption was initially made of the data to extract dominant themes. This was followed by dividing dominant themes into meaningful topics. Finally, the data were coded to put meaningful topics into categories. Field observational data were used to support interview data. Credibility was also enhanced by the analysis being conducted using investigator triangulation, as data were continuously discussed with all co-authors. To store, code and systematise data, Nvivo12 was applied. An overview of the analysis process is shown in Table 3.

Total impression—identifying themes	Identifying and sorting meaning units—from themes to codes	Condensation—from code to meaning	Synthesis—from condensation to descriptions and concepts
Descriptions of family	The meaning of having family members around you	Family plays a big role after discharge Family supports by listening, being	Implications of family involvement

		calm, practical issues	
		Family actions when symptoms occur	
		Caregiver burden	
		Family structure is rarely identified	

Table 3: An excerpt of the analysis process from one case. It shows the emergence of a main theme in a Danish study on the needs and preferences of patients and family members discharged from the emergency department within 24 hours.

Ethics

In accordance with the Helsinki Declaration and the Ethical Guidelines for Nursing Research [29], participants were asked both orally and in writing to grant consent. According to Danish legislation, this study did not need ethical approval from the National Committee on Health Research Ethics (REF: S-20192000-111). The study is registered with the 'Record of data process of Registry of Southern Denmark' (19/22672). Data were stored in SharePoint (Microsoft Corporation) AND OPEN_938.

Results

Participant descriptions

Field observational studies were conducted for 20 days (50 hours total; August to October 2020). Twenty-eight patients were asked permission to participate in the study, and four declined due to mental distress. Twenty-four patients accepted participation; however, one patient did not respond to the telephone call. Seven family members accepted. Nineteen interviews were conducted individually with patients, three with individual family members and four as joint interviews. Interviews were conducted at the

location that the patient and/or family member preferred, either by telephone (n=23) or at the patient's home (n=3).

Four themes were developed:

1. Being in a vulnerable place—emotional concerns
2. Person-centred information
3. The atmosphere in the emergency department
4. The implications of family involvement

Being in a vulnerable place—emotional concerns

Most of the patients expressed a sense of vulnerability while attending the ED. Some patients had been to the ED several times, but that did not necessarily make them more confident. Patients described feelings such as stress, anxiety and being afraid of what was going to happen. As a kind of defense mechanism, patients stated that they were looking for meaning in the situation. They compared the current situation with something to which they could relate, e.g., from their own or their social networks' experiences. Only a few patients shared their emotional thoughts with HCPs. Both patients and family members highlighted that they had the need for an approach that showed an understanding of their emotional concerns alongside physical symptoms. Many patients described the period from when acute symptoms began to arriving at the hospital as being a very dramatic experience.

> *I was admitted late in the evening yesterday. It is my third time here... Actually, I have been terrified since last time... You know, psychologically scared... (Informal interview during field observation, female patient in her 60s).*

Common to all patients and family members was the need for clear signals from HCPs. When finding themselves in such a stressful and tense situation, they wanted HCPs to navigate them through their stay in the ED by being precise and direct when communicating. Patients described the need for knowing what they were waiting for, as otherwise, unproductive thoughts about being severely ill came to their minds in addition to feelings of being forgotten by HCPs. The majority of the patients underlined that the stay in the ED was only a small part of their trajectory; the time before attending the ED

could have been very exhausting, and the time after discharge was filled with concerns or doubt related to the progress of the illness, new medication, and follow-ups.

> *From this experience, we agreed not to call the 'out of hours' service anymore. If it happens again, we will call 112 directly, and we have arranged with my mother-in-law to always have her telephone turned on in the night (husband in his 30s).*

Patients expressed that they were in a blurry state of mind, not able to remember details when returning to home. They described a need for follow up at their general practitioner, looking into the electronic record app from home or having family to help them remember elements in the treatment plan after discharge. Even if nurses and physicians were very thorough in communicating discharge information, patients seemed not to be able to remember things such as where to go for follow-up, what to do if they started feeling worse, future treatment plans, or how to manage new medication. Some patients explained that they had information overload in a very short period of time, and in relation to finding themselves in an unbalanced situation, they could not process as much as they normally would be able to. There was no difference in this sense across different ages.

> *At that moment, I did not realise, I had to ask when and how I should take the new medication… I had to call the ED the day after (female patient in her 40s).*

Person-centred information

Both patients and family members emphasised a desire for more information. They underlined a need for having things repeated frequently in plain language. Moreover, the uncertainty of being acutely ill seemed to intensify a need for knowing when changes in the treatment plan are made, and patients and family members asked for systems where they could follow 'live' updates of their journal. The participants expressed understanding of the limited time available to provide information when the department was busy but underlined that their need for information was still valid.

> *There I was, about to explode. I kept myself in control and asked if anyone had thought about telling ME about the changes in the plan. I had waited for eight*

hours and I was apparently the only one who did not know that the planned examination was changed (female patient in her 30s).

Those patients who found their information needs fulfilled described that HCPs had resources to collect the patient-reported data, listen to the patient in a genuine way, and inform them about expected examinations at the same time.

When the pictures from the scan were ready, the doctor sat beside me and commented on them in a way that I could understand. It could not have been done better (male patient in his 80s).

Experiences that helped patients and family members alleviate their burdens were related to information and communication levels. Secure verbal and nonverbal language from HCPs helped the patients deal with their situations.

The insecurity the doctor came in with… He was so shy and cautious… In this situation, I had the need for him to step forward and say: 'We are going to do this and this… and we have everything in control.' He failed to relieve the stress I was carrying on my shoulders (male patient in his 50s).

The participants described discharge information, but often only remembered specific details. When a clear discharge plan summarising health-related details was provided, this was often mentally challenging, making patients cope with too many details.

I could not keep up with the information. I know that I feel no pain now, and I recognise that they measured something in my blood… But I do not know what it was all about (male patient in his 90s).

Being chronically ill appeared to present diverse information needs. Family members and patients dealing with chronic disease expressed a need for HCPs to listen to them and plan a treatment linked to their previous experiences. It was important to see experienced nurses and physicians being able to handle symptoms and begin treatment without the need for consulting more experienced colleagues. 'Experienced' patients

and/or family members had a need for fast assessment, as they often knew what treatment would work, and they did not want to waste time in the hospital.

> *It is like they follow a manual instead of listening to me. Sometimes I just take the medication they always offer, even though I know, and have told them many times, that it does not take away MY pain (female patient in her 40s).*

The atmosphere in emergency departments

Aspects of a 'busy environment' were mentioned by all participants. Situations where patients were discharged by the physician but still waited for details on things like medications delayed them leaving the hospital. The participants described an uncomfortable sense of disturbing the nurse, as they knew they were busy, but on the other hand, they saw possibilities of making room for new patients if they just were given the details needed. Not many explanations or questions were given from the nurses in these hectic situations.

> *She looks at me and says: why is she (the nurse) not coming as we agreed to…should I call for her again….Maybe she gets angry with me…. She calls for the nurse again (fieldnote, September 2021).*

Being a patient in a busy environment provided insecurity if HCPs did not share which examinations were initiated, what the progress on these was, and what the estimated time was before a treatment plan could be formed. They found themselves trapped in a worrying situation with no options to find answers to clarify their speculations.

> *I tried many times to find out if the scan was booked. No one wanted to say anything… I know there must be some priority lists, but where I am on that? No one seemed to want to talk to me... I just wanted an estimate of how long it would take… That uncertainty—I really hope the time spent being uncertain could be reduced (male patient in his 50s).*

The participants highlighted how the HCPs' attitudes influenced how their needs were fulfilled, describing an ideal connection with the HCP as involving being seen as a person

rather than 'just another patient in the row'. Positive descriptions of HCPs' attitudes referred to them being friendly, showing genuine interest and communicating their professional '*stuff*' with patience. Negative attitudes also seemed to affect the time after discharge, as it entailed a need for processing the experience through conversation and discussion of the encounter.

> *It was frustrating that the doctor, a new doctor, came to send us home… He started to complain about how this was not his intended job, as he worked in another area of the hospital… That was frustrating to be met in that way and we talked a lot about his attitude after returning to home (husband in his 40s).*

Implications of family involvement

The participants explained that family presence in EDs provided support. Often, patients found themselves in a position where it was difficult to explain and keep track of details of what had happened before the acute symptoms occurred, and family members were able to provide those details.

> *I was pretty blurry, but my husband could tell them (HCP) about the past days, the operation and so on; that made me calm (female patient in her 50s).*

Family members of patients who had been in the ED many times could feel great frustration when their loved ones were discharged rapidly without any interventions or further treatment plans. They described a feeling of powerlessness without any means to affect the way forward, and they asked for a clear treatment plan or symptom control.

> *One time I went with her… I thought, now I really had to tell them… But I could not do anything… Nothing helped… We were sent home as all the other times (husband in his 40s).*

In many cases, family members played a central role after discharge. The patients who did not have family members nearby arranged for supportive telephone calls from neighbors or primary homecare. In some instances, the nurses in the ED recognised the patient's need for extra support after discharge, but this was the result of individual

judgments by the nurses. Family members described a need to be heard and genuinely involved in discharge plans. Family members who were not able to be physically present during the emergency admission stressed that they would like to be included in discussions regardless.

> *They did not listen to me; it was way too soon (to discharge). When we came home, it got worse. I couldn't even get her to the bathroom. I called 112 again, I couldn't handle the situation (son in his 50s).*

Discussion

Principal findings

We investigated the needs and preferences of patients discharged from the ED and their family members and found that they wanted health professionals to understand their **vulnerability.** They also preferred HCPs to engage in direct **communication** that was tailored to their level of understanding—especially information on waiting times and treatment plans. The **busy environment** caused doubts about control of their treatment plan and provided feelings of being 'just another patient' in the line. No specific **family inclusion strategy** was observed. However, a need for genuine family involvement in discharge plans was identified.

A gap between needs and organisation

Research has explored interventions to reduce overcrowding in the ED, placing a focus on patient flow and effective organisation [30, 31]. These changes might have a psychosocial cost, however, as we identified a gap between the needs of patients and family members and what the healthcare system currently delivers. Patients have several unmet needs, including information and psychosocial support during a time of vulnerability. A need for clear communication was also found by Rising et al. [32]. Rising et al. established a protocol for discharge communication in the ED, which included a 21-item checklist to provide improved support and training HCPs to possess person-centred

communication skills [32]. This could be a possible solution to reduce the gap between an effective and flow-focused environment and the need for clear communication.

Having unmet needs at the time of discharge was also explored by Samuels-Kalow et al., as they recognised that critical discharge information was often given in a time-limited environment [33]. To meet the needs of clear communication, they suggested implementing "protected and undisturbed time" for HCPs when entering a discharge conversation [34]. None of the studies explored the time after discharge. Our findings showed patients report difficulties remembering the provided information. Lack of recall caused patients to contact the ED, see their general practitioner or look at the electronic record app. Interventions to improve patient understanding after discharge were previously initiated in a qualitative American study, which suggested that patients follow up at home and revisit information [35]. However, these findings differ from a Danish randomised study by Lisby et al., which explored services such as telephone follow-up and discharge letters [8]. They found that telephone follow-up did not show a significant effect on patients' experiences of discharge [8]. These interventions did not seem to reduce the gap between patient needs and what the current health care system is able to deliver.

A main finding in our study was the need to identify the vulnerability of the patients and family. Therefore, we suggest that future interventions include tailored communication and a person-centred approach based on an understanding of the underlying sense of vulnerability acute patients and family members suffer from. Vaillancourt et al. 2017 developed a conceptual model of ED care in which they found that patients have a need for HCPs to recognise their emotional worries [6]. A meta-synthesis on ED patient experience found that the ED environment must be customised if patients' emotional needs are to be met [36]. They emphasised a request for knowledge about 'patient suffering' from anxiety and fear in the ED and its implications [36]. In parallel, a Danish study exploring hip-facture management also identified a gap between what the healthcare system provides, and patients' needs when they are in a shock-like state of mind [37]. Similar to our findings, they stressed a need for more individual targeted means of informing and educating patients to meet their needs [37].

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Therefore, our findings create an awareness of the vulnerable state of mind acute patients possess. From this knowledge, the feasibility of developing future interventions to accommodate needs in the ED might be improved.

A need for genuine family involvement in the ED

Family members in our study described a need for genuine involvement and recognition by HCPs. Family members play a central role during a patient's illness. They help patients 'translate' care and need to be included in treatment and care planning. Similar research has reported that family members are recognised as a resource in the ED [11, 38]. Family members can assist with practical and emotional support, but direct involvement in care is lacking, especially in busy periods [11, 39].

A lack of genuine involvement was also identified in our study, resulting in frustrations and feelings of powerlessness. Our findings highlight that for family members to be a resource, they need to be involved in discussions to ensure fundamental details related to the patient course of treatment are not missed, leading to readmission. To promote genuine family involvement in care, a systematic approach towards family inclusion should be introduced and HCPs trained in family-focused communication [40, 41]. Genuine involvement with families might reduce the uncertainty associated with the illness experience and increase the ability to self-manage at home [42]. One strength of our study was the triangulation of patient and family member perspectives combined with field observations. This introduces a broad perspective into the research. The inclusion of two sites with no notable differences in participants' statements further strengthens the validity of the findings. The study constitutes an important and crucial step towards an understanding of how to design interventions to improve family-centred care. The next phase of this three-phased study will be a co-design development of an intervention to meet the needs of patients and family members.

Limitations:

Synthesizing field observations and interviews can be difficult, but the researcher followed an observational guide and systematic analysis process. Most interviews were conducted over the telephone due to Covid-19 risks, preventing the interviewer from

seeing facial expressions or body language [25]. However, from the dynamic of the conversations, we do not think that important expressions were missed. Taking ED patients as the study population represents diversity: even though we only included a small sample size, we found clear patterns across the interviews. Our study participants were from wealthier socioeconomic areas with few ethnic minorities represented, which may have caused selection bias. Therefore, validating our findings in a minority patient group would have strengthened our findings.

Conclusion:

This study demonstrates that there is a gap between the needs of patients and family members and what the emergency department delivers. The findings highlight the importance of future interventions to include person-centred information with genuine involvement of family members. The vulnerability of patients and family needs to be acknowledged and included in the design of interventions.

Table labels:

Table 1: Participant characteristics of patients in a Danish Study on needs and preferences of patients and family members discharged from the emergency department within 24 hours.

Table 2: Participant characteristics of family members in a Danish study on needs and preferences of patients and family members discharged from the emergency department within 24 hours.

Table 3: Table 3: An excerpt of the analysis process from 1 case. Showing the emergence of a main theme in a Danish study on needs and preferences of patients and family members discharged from the emergency department within 24 hours.

Competing interests: There are no competing interests**.**

Author contribution: CMJ, KBD, EC, ATL and CØ designed the study. CØ collected data. CMJ, KBD, and CØ performed the analysis. CØ took the lead in drafting the manuscript; all authors commented and gave feedback. All authors approved the final version of the manuscript.

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References

1. Forero, R., et al., *Perceptions and experiences of emergency department staff during the implementation of the four-hour rule/national emergency access target policy in Australia: a qualitative social dynamic perspective.* BMC Health Serv Res, 2019. **19**(1): p. 82.

2. Sundhedsstyrelsen, Danske Regioner, and Sundheds og Ældreministeriet, *De danske akutmodtagelser. Statusrapport 2016.* 2017.

3. Han, C.Y., A. Barnard, and H. Chapman, *Discharge planning in the emergency department: a comprehensive approach.* J Emerg Nurs, 2009. **35**(6): p. 525-7.

4. Nielsen, L., et al., *Returning to everyday life after discharge from a short-stay unit at the Emergency Department-a qualitative study of elderly patients' experiences.* Int J Qual Stud Health Well-being, 2019. **14**(1): p. 1563428.

5. Stevens, L., et al., *Fast track patients' satisfaction, compliance and confidence with emergency department discharge planning.* Australas Emerg Care, 2019. **22**(2): p. 87-91.

6. Vaillancourt, S., et al., *Patients' Perspectives on Outcomes of Care After Discharge From the Emergency Department: A Qualitative Study.* Ann Emerg Med, 2017. **70**(5): p. 648-658.e2.

7. Kremers, M.N.T., et al., *Patient's perspective on improving the quality of acute medical care: determining patient reported outcomes.* BMJ Open Qual, 2019. **8**(3): p. e000736.

8. Lisby, M., et al., *Clinical impact of a comprehensive nurse-led discharge intervention on patients being discharged home from an acute medical unit: Randomised controlled trial.* Int J Nurs Stud, 2019. **100**: p. 103411.

9. Levine, D.M., et al., *Hospital-Level Care at Home for Acutely Ill Adults: A Randomized Controlled Trial.* Ann Intern Med, 2020. **172**(2): p. 77-85.

10. Johannessen, A.K. and S. Steihaug, *Municipal Acute Units as Part of the Clinical Pathway for Older Patients.* Int J Integr Care, 2019. **19**(4): p. 2.

11. Hoffmann, E. and P.R. Olsen, *Like an ace up the sleeve: an interview study of nurses' experiences of the contact with relatives in a somatic emergency ward.* Scand J Caring Sci, 2018. **32**(3): p. 1207-1214.

12. Elmqvist, C. and C. Frank, *Patients' strategies to deal with their situation at an emergency department.* Scand J Caring Sci, 2015. **29**(1): p. 145-51.

13. Mackie, B.R., A. Marshall, and M. Mitchell, *Acute care nurses' views on family participation and collaboration in fundamental care.* J Clin Nurs, 2018. **27**(11-12): p. 2346-2359.

14. Mackie, B.R., M. Mitchell, and A.P. Marshall, *Patient and family members' perceptions of family participation in care on acute care wards.* Scand J Caring Sci, 2018.

15. Demidenko, J., et al., *Family functioning evaluated by family members of older patients and nurses in emergency departments.* Scand J Caring Sci, 2018. **32**(3): p. 1064-1073.

16. Cetin-Sahin, D., et al., *Experiences of an Emergency Department Visit Among Older Adults and Their Families: Qualitative Findings From a Mixed-Methods Study.* J Patient Exp, 2020. **7**(3): p. 346-356.

17. Hsiao, P.R., et al., *Family needs of critically ill patients in the emergency department.* Int Emerg Nurs, 2017. **30**: p. 3-8.

18. Curran, J., et al., *Patient and caregiver expectations of emergency department care: A scoping literature review.* Int Emerg Nurs, 2017. **32**: p. 62-69.

19. Simonsen, J. and T. Robertson, *Routledge international handbook of participatory design*. 2012: Routledge.

20. Østervang, C., et al., *How to improve emergency care to adults discharged within 24 hours? Acute Care planning in Emergency departments (The ACE study): a protocol of a participatory design study.* BMJ Open, 2020. **10**(12): p. e041743.

21. Green, J. and N. Thorogood, *Qualitative methods for health research.* . 3rd edition. ed. 2014: Sage. .

22. Tong, A., P. Sainsbury, and J. Craig, *Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups.* Int J Qual Health Care, 2007. **19**(6): p. 349-57.

23. DEPT. *User Manuel Danish Emergency Process Triage - DEPT*. Available from: http://deptriage.dk/brugervejledning/.

24. Moser, A. and I. Korstjens, *Series: Practical guidance to qualitative research. Part 3: Sampling, data collection and analysis.* Eur J Gen Pract, 2018. **24**(1): p. 9-18.

25. Kvale S and Brinkmann S, *Interview: introduktion til et håndværk.* . 2009, Kbh.: Hans Reitzel.

26. Spradley, J., *Participant Observation*. 2016, Long Grove, : waveland Press.

27. Zarhin, D., *Conducting Joint Interviews With Couples: Ethical and Methodological Challenges.* Qual Health Res, 2018. **28**(5): p. 844-854.

28. Malterud K, *Kvalitative metoder i medisinsk forskning*. 2014, Osla: Univeristetsforlaget.

29. Sykepleiernes Samarbeid i Norden Northern Nurses Federation, *Ethical guidelines for nursing research in the Nordic countries.* 2003.

30. Bittencourt, R.J., et al., *Interventions in overcrowding of emergency departments: an overview of systematic reviews.* Rev Saude Publica, 2020. **54**: p. 66.

31. De Freitas, L., et al., *Interventions to improve patient flow in emergency departments: an umbrella review.* Emerg Med J, 2018. **35**(10): p. 626-637.

32. Rising, K.L., et al., *Development of the Uncertainty Communication Checklist: A Patient-Centered Approach to Patient Discharge From the Emergency Department.* Acad Med, 2020. **95**(7): p. 1026-1034.

33. Samuels-Kalow, M., et al., *Unmet Needs at the Time of Emergency Department Discharge.* Acad Emerg Med, 2016. **23**(3): p. 279-87.

34. Marzorati, C., et al., *Telemedicine Use Among Caregivers of Cancer Patients: Systematic Review.* J Med Internet Res, 2018. **20**(6): p. e223.

35. Rising, K.L., et al., *"I'm Just a Patient": Fear and Uncertainty as Drivers of Emergency Department Use in Patients With Chronic Disease.* Ann Emerg Med, 2016. **68**(5): p. 536-543.

36. Graham, B., et al., *'They do not care how much you know until they know how much you care': a qualitative meta-synthesis of patient experience in the emergency department.* Emerg Med J, 2019. **36**(6): p. 355-363.

37. Jensen, C.M., et al., *Empowerment of whom? The gap between what the system provides and patient needs in hip fracture management: A healthcare professionals' lifeworld perspective.* Int J Orthop Trauma Nurs, 2020. **38**: p. 100778.

38.   Barreto, M.D.S., et al., *Meanings attributed by family and patients to family presence in emergency rooms.* Rev Bras Enferm, 2019. **72**(6): p. 1684-1691.

39.   Forsgarde, E.S., M. From Attebring, and C. Elmqvist, *Powerlessness: Dissatisfied patients' and relatives' experience of their emergency department visit.* Int Emerg Nurs, 2016. **25**: p. 32-6.

40.   Naef, R., et al., *Implementing Family Systems Care Through an Educational Intervention With Nurses and Midwives in Obstetrics and Gynecological Care: A Mixed-Methods Evaluation.* J Fam Nurs, 2020. **26**(2): p. 138-152.

41.   Wright, L.M. and M. Leahey, *Maximizing time, minimizing suffering: The 15-minute (or less) family interview. .* Journal of Family Nursing, 1999. **5(3),**: p. 259-274.

42.   Emmamally, W., C. Erlingsson, and P. Brysiewicz, *Partnering with families: Is the ED ready?* Int Emerg Nurs, 2019. **42**: p. 1.

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Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the inter view or focus group?	
Duration	21	What was the duration of the inter views or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

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What are the needs and preferences of patients and family members discharged from the emergency department within 24 hours? A qualitative study towards a family-centred approach

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Title

What are the needs and preferences of patients and family members discharged from the emergency department within 24 hours? A qualitative study towards a family-centred approach

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Abstract

Objective: There is an increase in patients being discharged after short stays in the emergency department, but there is limited knowledge of their perspectives on treatment and care. This study aims to explore and understand the needs and preferences of emergency care from the perspective of patients and family members discharged from the emergency department within 24 hours of admission.

Design: This was a qualitative study using systematic text condensation to identify key themes from field observations and interviews with patients and family members.

Setting: This study was conducted in two emergency departments in the Region of Southern Denmark.

Participants: All adults aged ≥18 years who had been discharged from the emergency department within 24 hours were eligible to take part. Purposeful sampling was used to recruit patients and family members with different sociodemographic features.

Results: Field observational studies (n=50 hours), individual interviews with patients (N=19) and family members (N=3), and joint interviews with patients and family members (N=4) were carried out. Four themes were derived from the material: 1) being in a vulnerable place— having emotional concerns; 2) having a need for person-centred information; 3) the atmosphere in the emergency department; and 4) implications of family presence.

Conclusion: This study demonstrates a gap between patients' and family members' needs and preferences and what current emergency departments deliver. The findings highlight the importance of family and person-centred care. Tailored communication and information with genuine involvement of family members is found to be essential needs during acute illness.

Strengths and limitations

- o The findings and methodological approaches in the study have been critically evaluated and discussed by experienced researchers from different fields of research.

- o Data were generated using different methods and involved a broad representation of participants to ensure robust findings.

- o Quotations support the trustworthiness of the findings.

- o Although there is a thorough description of the research process to support credibility, descriptions of the findings are contextual and reflect a Danish context.

Introduction

Internationally, many countries comparable to Denmark, such as the United Kingdom and Australia, work to establish an organisational structure in emergency departments (ED) to prevent overcrowding and access blockage [1]. A four-hour rule was introduced in EDs for practitioners to develop a plan of treatment: either admission or discharge was expected within four hours [1]. Across 21 Danish EDs, the same structure exists to promote clinical assessment and treatment plans of patients within four hours, a short stay in a Danish ED typically range from <4 - 48 hours [2]. However, a lack of thoroughness in the delivery of information and assessment of patients' and family members' individual needs may result in patients being discharged from the ED who are unable to maintain their health status [3, 4]. The environment in EDs is challenging, with a diversity of health needs to be met [5]. Patient-reported outcomes were explored across two studies, and four outcomes were identified: an understanding of one's condition, symptom relief, reassurance and a treatment plan [6, 7]. Both studies targeted patient-reported measures to improve acute care but did not include the family perspective [6, 7]. Interventions related to patient outcomes are limited or focus on reducing re-admission rather than satisfying needs and preferences [8].

Globally, many initiatives focus on out-of-hospital care, such as hospital at home, telehealth and outpatient clinics to support ongoing treatment initiated in the hospital as well to support early discharge [9, 10]. Therefore, family members play an active role in maintaining patient outcomes after early discharge to homes [11, 12]. Mackie et al. found

in a qualitative study that health professionals identified the advantage of family participation in care for enhancing the quality of care and improving patient satisfaction [13, 14]. However, research on the needs of family members involved in short visits to EDs is sparse or focuses on elderly patients [15, 16]. To date, little is known of how patients and families experience short-term stays in the ED and what needs and preferences they have [17, 18]. In the interest of organising and practicing tailored care, it is essential to explore the needs and preferences of patients and their family members to ensure that the care provided is valuable.

Objective

This study aims to explore and understand the needs and preferences of emergency care from the perspective of patients and family members discharged from the Emergency department within 24 hours of admission.

Methods

Study design

Participatory design (PD) is this study's research methodology [19]. PD has a phenomenological and hermeneutical stance using qualitative methods towards understand lived experiences and needs of individuals[19, 20]. As methods, field observations and interviews with patients and family members were chosen. This study is the first phase of a three-phase project [21].Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups were used as guidelines[22].

Patient involvement

The local patient and family member council have read the study protocol and gave suggestions for improvements.

Setting

The study was conducted in EDs at two hospitals in the Region of Southern Denmark:

1) Odense University Hospital (OUH), a 1,000-bed university hospital that covers all specialties. The ED has 69,000 annual attendees. On average, 32 patients are admitted per day, and 50% are discharged within 24 hours.

2) The Department of Emergency Medicine, Hospital of Lillebaelt, Kolding. The Hospital of Kolding has 320 beds. The ED has 50,000 annual attendees and receives 146 patients per day.

Visitor restrictions due to Covid-19 were in place in 2020, and only one family member was allowed in the ED.

Participants

Eligibility criteria: Patients were Danish-speaking individuals ≥ 18 years old with a medical or surgical diagnosis who had been discharged from the ED after less than 24 hours. Family members accepted by the patient were included.

Exclusion criteria: Patients with cognitive impairment as evaluated by an individual clinical judgement according to their ability to comprehend the terms of participating were excluded. Patient triaged at the highest and lowest triage level as per the Danish Emergency Process Triage were excluded [23]. The highest triage level is received care in trauma room and not expected to be discharged within 24 hours. The lowest triage level is received care for minor cut or concern by either a nurse or a physician with no examinations.

Sample size: A target minimum sample was 20 patient, but data collection continued until thematic saturation [24] as well as completing a pre-defined target group (table 1). No specific target sample was set for family members. Features were defined by the research group to ensure diversity represented.

Patients (n=20)

Age	10 patients ≥65 years of age 10 patients ≤65 years of age
Sex	10 females 10 males
Symptoms	10 patients having surgical symptoms 10 patients medical symptoms

Education level	10 patients with education level above secondary school
	10 patients with education level below secondary school
Function level	10 patients receiving primary care
	10 patients not receiving primary care
Social status	10 living on their own in independent accommodation
	10 living together with someone
Frequency of stay	10 having their first visit in the ED
	10 having more than one visit in the ED

Table 1: Patient features representing the target group population.

Data collection

Data collection was carried out by CØ, who has thirteen years of experience in nursing and holds a Master of Science in Nursing. She had no care responsibilities for any of the patients admitted to the ED.

Researcher characteristics and reflexivity

A phenomenological-hermeneutical approach allowed CØ to recognize her perceptions as an experienced emergency nurse within hermeneutic interpretation [25]. To enable recognition of the researchers preconceived ideas CØ wrote down her preunderstanding of why patients lack information being discharged and might have many concerns[26]. This reflection provided an initial focus for research questions [26].

Recruitment

Eligible patients and their family members were purposively recruited between August 9th and October 29th, 2020 by the first author (CØ). In both EDs a nurse coordinator keeps an overview of available rooms, in and out hospital transfers and expected length of stay for each patient in close collaboration with the emergency physicians. CØ discussed the target group population with the nurse coordinator to identify potential participants. No time restriction related to how long the patients had stayed in the ED was set. After identifying a potential participant CØ talked to the nurses who provided the care and they asked for the patient's permission for CØ to approach the patient. If accepted, CØ

informed the patient and/or family members orally and in writing about the study. At the end of the observation all participants were asked for consent for one interview within the first week after discharge.

Field observational studies

Field observations helped the authors to understand how the interactions and activities in the ED informed experiences, needs and preferences [25]. Furthermore, it provided first-hand knowledge of consistency between what actually happened during the participants interaction with health professionals in emergency and what was said by participants in the interviews[25]. Inspired by Spradley's nine dimensions, [27] an observational guide was designed and pilot-tested in two cases. The observational guide contained several points including human interactions, time and events in the ED. CØ was present at the EDs for three to six hours per day, during both morning and evening shifts, and made observations in medical and surgical areas. CØ followed the patients during their stay joining them in the hospital room, examinations and other areas the participant required treatment. Duration of the observations varied in respect for the patient's wishes from 30 minutes to 4 hours. Field notes were written each day containing observations and quotes.

Interviews

To gain an understanding of the needs and preferences expressed, the observations were supplemented with interviews. Both individual and joint interviews were utilised, as the study aimed to explore both the perspectives of the patients and family members as well as their joined needs. The authors wanted to give the participants the power to decide which interview form they preferred. Therefore, interviews were conducted as face-to-face, telephone, individual or joint interviews according to participant preference and to accommodate the Covid-19 induced restrictions. All interviews were conducted using an interview guide inspired by Kvale and Brinkmann [28], recorded and transcribed. The guide was developed based on the identified scientific literature on the topic and the preliminary results of field observations. An example of an interview question is: "What significance does family have in your lives?"

Data from the observations were used directly in the interview e.g. "At the end of the stay you talked to a nurse, can you tell me about that experience?"

At the end of the interview, the interviewer summarized the interview and checked with the participant to ensure correct interpretation. Participants were asked if they would like to read the transcript. Two participants accepted with no further comments. The interview guide was pilot tested with two cases. Interviews were conducted one time, two to seven days after discharge.

Analysis

The analysis was performed according to systematic text condensation [29]. An overall caption was initially made of the data to extract dominant themes. This was followed by dividing dominant themes into meaningful topics. Finally, the data were coded to put meaningful topics into categories. Field observational data were used to support interview data. The data from field observations and the interviews were analysed separately and then combined across the participant interaction to understand the deeper aspects of health professional interchanges with participants and the participants recollection of the interaction and information. After step four all data were synthesized. CØ was in charge of the coding process. During the coding process the author group met to discuss the codes as strategy to mitigate potential bias. Credibility was also enhanced by the analysis being conducted using investigator triangulation, as data were continuously discussed with all co-authors. NVivo12 was used to store, code and systematise data.

Ethics

In accordance with the Helsinki Declaration and the Ethical Guidelines for Nursing Research [30], participants were asked both orally and in writing to grant consent. According to Danish legislation, this study did not need ethical approval from the National Committee on Health Research Ethics (REF: S-20192000-111). The study is registered with the 'Record of data process of Registry of Southern Denmark' (19/22672). Data were stored in SharePoint (Microsoft Corporation) AND OPEN_938.

Results

Participant descriptions

Field observational studies were conducted for 20 days (50 hours total; August to October 2020). Twenty-eight patients were asked permission to participate in the study, and four declined due to mental distress. Twenty-four patients accepted participation(table 2); however, one patient did not respond to the telephone call. Seven family members accepted (table 3). Nineteen interviews were conducted individually with patients, three with individual family members and four as joint interviews. To achieve enrollment across all target groups recruitment continued until 24 patients were enrolled.

Patient characteristics	N (%)
Gender *Male* *Female*	9 (37.5) 15 (62.5)
Age *1 –35* *36–49* *50–65* *66–80* *81 or older*	3 (12.5) 5 (20.8) 5 (20.8) 6 (25.0) 5 (20.8)
Living situation *Living alone* *Living with others*	11 (45.8) 13 (54.2)
Nationalities represented in the study	4 (100)
Education level *Below secondary school* *Above secondary school*	11 (45.8) 13 (54.2)
Function level *Receives primary homecare* *No help needed*	9 (37.5) 15 (62.5)
Method of admittance *By ambulance* *Attending the ED alone* *Attending the ED with family members*	15 (62.5) 5 (20.8) 4 (16.7)
Family in the ED *Yes* *No*	13 (54.2) 11 (45.8)
Frequency of stay *First time in ED*	9 (37.5)

More than one visit in the ED	15 (62.5)
Main symptoms	
Medical	10 (41.7)
Surgical	6 (25.0)
Neurological	3 (12.5)
Orthopedic	4 (16.7)
Gynecological	1 (4.2)
Co-morbidity	
Yes	13 (54.2)
No	11 (45.8)

Table 2: Characteristics of participating patients in a Danish study on needs and preferences of patients and family members discharged from the emergency department within 24 hours

Family member characteristics	**N (%)**
Gender	
Male	4
Female	3
Mean age (years)	55
Family relation to patient	
Daughter	1
Son	1
Spouse	4
Parent	1
Education level	
Below secondary school	3
Above secondary school	4

Table 3: Characteristics of participating family members in a Danish study on needs and preferences of patients and family members discharged from the emergency department within 24 hours

Interviews were conducted at the location that the patient and/or family member preferred, either by telephone (n=23) or at the patient's home (n=3).

Four themes were developed:

1. Being in a vulnerable place— having emotional concerns

2. Having a need for person-centred information

3. The atmosphere in the emergency department

4. The implications of family involvement

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Being in a vulnerable place—having emotional concerns

Most of the patients expressed a sense of vulnerability while attending the ED. Some patients had been to the ED several times, but that did not necessarily make them more confident. Patients described feelings such as stress, anxiety and being afraid of what was going to happen. Only a few patients shared their emotional thoughts with HCPs. Both patients and family members highlighted that they had the need for an approach that showed an understanding of their emotional concerns alongside physical symptoms.

> *I was admitted late in the evening yesterday. It is my third time here... Actually, I have been terrified since last time... You know, psychologically scared... (Informal interview during field observation, female patient in her 60s).*

Similar for patients and family members was the need for clear signals from HCPs. When finding themselves in such a stressful and tense situation, they wanted HCPs to navigate them through their stay in the ED by being precise and direct when communicating. Patients described the need for knowing what they were waiting for, as otherwise, unproductive thoughts about being severely ill came to their minds in addition to feelings of being forgotten by HCPs.

> *Waiting time is hard... You do not know what is happening, and you speculates if they (HCPs) soon will find out.... I am all alone with my thoughts (female patient in her 80s).*

The majority of the patients underlined that the stay in the ED was only a small part of their trajectory; the time before attending the ED could have been very exhausting, and the time after discharge was filled with concerns or doubt related to the progress of the illness, new medication, and follow-ups.

> *She talks in the phone. She says that no one asked if she was able to handle things at home. "But I need home care, how do we do this?" she asked her family during the phone conversation (fieldnote, October 2020).*

Patients expressed that they were in a blurry state of mind, not able to remember details when returning to home. They preferred a follow up at their general practitioner, looking into the electronic record app from home or having family to help them remember elements in the treatment plan after discharge. Even if nurses and physicians strived to be thorough in communicating discharge information, patients seemed not to be able to remember things such as where to go for follow-up, what to do if they started feeling worse, future treatment plans, or how to manage new medication.

> *The physician is having a long conversation with him. Pleasant atmosphere. They both smile. They have eye contact. They agree on the plan of discharge (fieldnote, August 2020).*
>
> *I only remember that I was not allowed to drive, but actually I do not know for how long? (Patient talking about his experience reflected in the fieldnote, male in this 60s).*

Some patients explained that they had information overload in a very short period of time, and in relation to finding themselves in an unbalanced situation, they could not process as much as they normally would be able to. There was no difference in this sense across different ages. Family members did not describe the same issues.

> *At that time, I did not realise, I had to ask when and how I should take the new medication… I had to call the ED the day after (female patient in her 40s).*

Having a need for person-centred information

Both patients and family members emphasised a desire for more information. Especially, the patients preferred having things repeated frequently in plain language. Moreover, the uncertainty of being acutely ill seemed to intensify a need for knowing when changes in the treatment plan are made. Both patients and family members would have preferred a system where they could follow 'live' updates of the journal.

> *The patient and her husband talks about wanting access to the electronic journal while we are in the hospital (fieldnote, September 2020).*

The participants expressed understanding of the limited time available to provide information when the department was busy but underlined that their need for information was still valid.

> *There I was, about to explode. I kept myself in control and asked if anyone had thought about telling ME about the changes in the plan. I had waited for eight hours and I was apparently the only one who did not know that the planned examination was changed (female patient in her 30s).*

Those patients who found their information needs fulfilled described that HCPs had resources to collect the patient-reported data, listen to the patient in a genuine way, and inform them about expected examinations at the same time.

> *When the pictures from the scan were ready, the physician sat beside me and commented on them in a way that I could understand. It could not have been done better (male patient in his 80s).*

Experiences that helped patients and family members alleviate their burdens were related to information and communication levels. Secure verbal and nonverbal language from HCPs was preferred by the patients as it helped deal with their situations.

> *The insecurity the physician came in with… He was so shy and cautious… In this situation, I had the need for him to step forward and say: 'We are going to do this and this… and we have everything in control.' He failed to relieve the stress I was carrying on my shoulders (male patient in his 50s).*

Being chronically ill appeared to present diverse information needs. Family members and patients dealing with chronic disease expressed a need for HCPs to listen to them and plan a treatment linked to their previous experiences. Patients preferred to see experienced nurses and physicians being able to handle symptoms and begin treatment without the need for consulting more experienced colleagues.

> *It is like they follow a manual instead of listening to me. Sometimes I just take the*
> *medication they always offer, even though I know, and have told them many times,*
> *that it does not take away MY pain (female patient in her 40s).*

The atmosphere in emergency departments

Aspects of a 'busy environment' were mentioned by all participants. Situations where patients were discharged by the physician but still waited for details on things like medications delayed them leaving the hospital. The patients described an uncomfortable sense of disturbing the nurse, as they knew they were busy, but on the other hand, they saw possibilities of making room for new patients if they just were given the details needed.

> *She looks at me and says: why is she (the nurse) not coming as we agreed*
> *to…should I call for her again….Maybe she gets angry with me…. She calls for the*
> *nurse again (fieldnote, September 2020).*

Being a patient in a busy environment provided insecurity if HCPs did not share which examinations were initiated, what the progress on these was, and what the estimated time was before a treatment plan could be formed. They found themselves trapped in a worrying situation with no options to find answers to clarify their speculations. Better clarity of the progress was primary preferred by the patients.

> *I tried many times to find out if the scan was booked. No one wanted to say*
> *anything… I know there must be some priority lists, but where I am on that? No one*
> *seemed to want to talk to me… I just wanted an estimate of how long it would*
> *take… That uncertainty—I really hope the time spent being uncertain could be*
> *reduced (male patient in his 50s).*

The participants highlighted how the HCPs' attitudes influenced how their needs were fulfilled, describing an ideal connection with the HCP as involving being seen as a person rather than 'just another patient in the row'. Negative attitudes also seemed to affect the time after discharge, as it entailed a need for processing the experience through conversation and discussion of the encounter.

It was frustrating that the physician, a new one, came to send us home… He started to complain about how this was not his intended job, as he worked in another area of the hospital… That was frustrating to be met in that way and we talked a lot about his attitude after returning to home (husband in his 40s).

Implications of family involvement

The participants explained that family presence in EDs provided support. Often, patients found themselves in a position where it was difficult to explain and keep track of details of what had happened before the acute symptoms occurred, and family members were able to provide those details.

I was pretty blurry, but my husband could tell them (HCP) about the past days, the operation and so on; that made me calm (female patient in her 50s).

Family members of patients who had been in the ED many times could feel great frustration when their loved ones were discharged rapidly without any interventions or further treatment plans. They described a feeling of powerlessness without any means to affect the way forward, and they asked for a clear treatment plan or symptom control.

One time I went with her… I thought, now I really had to tell them… But I could not do anything… Nothing helped… We were sent home as all the other times (husband in his 40s).

In many cases, family members played a central role after discharge. The patients who did not have family members nearby arranged for supportive telephone calls from neighbors or primary homecare. In some instances, the nurses in the ED recognised the patient's need for extra support after discharge, but this was the result of individual judgments by the nurses.

A nurse enters the hospital room, she tells the patient that she have tried to reach the primary homecare by phone but did not succeed. She asks if the patient could call them herself when she comes home (fieldnote, October 2020).

Family members described a need to be heard and genuinely involved in discharge plans and patients preferred if they had family they would like to involve. Family members who were not able to be physically present during the emergency admission stressed that they would like to be included in discussions regardless.

> *They did not listen to me; it was way too soon (to discharge). When we came home, it got worse. I couldn't even get her to the bathroom. I called 112 again, I couldn't handle the situation (son in his 50s).*

Discussion

Principal findings

We investigated the needs and preferences of patients discharged from the ED and their family members and found that they wanted health professionals to understand their vulnerability. They also preferred HCPs to engage in direct communication that was tailored to their level of understanding—especially information on waiting times and treatment plans. The busy environment caused doubts about control of their treatment plan and provided feelings of being 'just another patient' in the line. No specific strategy for including family in the interactions with health professionals was observed, however, a need for genuine family involvement in discharge plans was identified.

A gap between needs and organisation

Research has explored interventions to reduce overcrowding in the ED, placing a focus on patient flow and effective organisation [31, 32]. These changes might have a psychosocial cost, however, as we identified a gap between the needs of patients and family members and what the healthcare system currently delivers. Patients have several unmet needs, including information and psychosocial support during a time of vulnerability. A need for clear communication has also been found in previous research [33-35]. A protocol for discharge communication in the ED, could support and train HCPs to possess person-centred communication skills [33]. Moreover, implementing a "protected and undisturbed time" for HCPs when entering a discharge conversation [34]. This could be a possible solution to reduce the gap between an effective and flow-focused

environment and the need for clear communication. Our findings showed patients report difficulties remembering the provided information. Lack of recall caused patients to contact the ED, see their general practitioner or look at the electronic record app. Interventions to improve patient understanding after discharge were previously initiated in a qualitative American study, which suggested that patients follow up at home and revisit information [36]. However, these findings differ from a Danish randomised study by Lisby et al., which explored services such as telephone follow-up and discharge letters [8]. They found that telephone follow-up did not show a significant effect on patients' experiences of discharge [8]. These interventions did not seem to reduce the gap between patient needs and what the current health care system is able to deliver.

A main finding in our study was the need to identify the vulnerability of the patients and family. Therefore, we suggest that future interventions include tailored communication and a person-centred approach based on an understanding of the underlying sense of vulnerability acute patients and family members suffer from. Vaillancourt et al. 2017 developed a conceptual model of ED care in which they found that patients have a need for HCPs to recognise their emotional worries [6]. A meta-synthesis on ED patient experience found that the ED environment must be customised if patients' emotional needs are to be met [37]. They emphasised a request for knowledge about 'patient suffering' from anxiety and fear in the ED and its implications [37]. In parallel, a Danish study exploring hip-facture management also identified a gap between what the healthcare system provides, and patients' needs when they are in a shock-like state of mind [38]. Similar to our findings, they stressed a need for more individual targeted means of informing and educating patients to meet their needs [38].

Therefore, our findings create an awareness of the vulnerable state of mind acute patients possess. From this knowledge, the feasibility of developing future interventions to accommodate needs in the ED might be improved.

A need for genuine family involvement in the ED

Family members in our study described a need for genuine involvement and recognition by HCPs. Family members play a central role during a patient's illness. They help patients

'translate' care and need to be included in treatment and care planning. Similar research has reported that family members are recognised as a resource in the ED [11, 39]. Family members can assist with practical and emotional support, but direct involvement in care is lacking, especially in busy periods [11, 40].

A lack of genuine involvement was also identified in our study, resulting in frustrations and feelings of powerlessness. Our findings highlight that for family members to be a resource, they need to be involved in discussions to ensure fundamental details related to the patient course of treatment are not missed, leading to readmission. To promote genuine family involvement in care, a systematic approach towards family inclusion should be introduced and HCPs trained in family-focused communication [41, 42]. Genuine involvement with families might reduce the uncertainty associated with the illness experience and increase the ability to self-manage at home [43]. One strength of our study was the triangulation of patient and family member perspectives combined with field observations. This introduces a broad perspective into the research. The inclusion of two sites with no notable differences in participants' statements further strengthens the validity of the findings. The study constitutes an important and crucial step towards an understanding of how to design interventions to improve family-centred care. The next phase of this three-phased study will be a co-design development of an intervention to meet the needs of patients and family members.

Limitations

Data collection by a single researcher was a potential bias, but did also ensure reliability in data collection. Also, synthesizing field observations and interviews can have potential bias. To provide rigour an observational guide and a systematic analysis process was followed[44]. Moreover, methodological and investigator triangulation were applied to support credibility[44]. Telephone interviews prevented the interviewer from seeing facial expressions or body language [28]. Therefore, an interview summarize was made along with offering participants to read the transcripts. At the time of the study, COVID 19 restrictions allowed presence from one family member. We enrolled family members present in the hospital, which could have caused the small sample size and could also have caused selection bias. Moreover, our study participants were from wealthier socioeconomic areas with few ethnic minorities represented. Therefore, validating our findings in a minority patient group would have strengthened our findings. For future

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research similarities and differences in the needs of patients and family members could create a broader understanding of emergency care. Furthermore, we did not include patients with cognitive impairment due to the complexity of the patient category; this is suggested for future research.

Conclusion

This study demonstrates that there is a gap between the needs and preferences of patients and family members and what the emergency department delivers. The findings highlight patient and family members need an increased focus on them being in a vulnerable state of mind having needs and preferences for person-centred information with genuine involvement of family members.

Table labels:

Table 1: Patient features representing the target group population.

Table 2: Participant characteristics of patients in a Danish Study on needs and preferences of patients and family members discharged from the emergency department within 24 hours.

Table 3: Participant characteristics of family members in a Danish study on needs and preferences of patients and family members discharged from the emergency department within 24 hours.

Competing interests: There are no competing interests**.**

Author contribution: CMJ, KBD, EC, ATL and CØ designed the study. CØ collected data. CMJ, KBD, and CØ performed the analysis. CØ took the lead in drafting the manuscript; all authors commented and gave feedback. All authors approved the final version of the manuscript.

Patient consent: Consent was obtained from all patients.

Data sharing statement: Data can be shared on reasonable request.

Supplementary file: The study protocol can be accessed: Østervang C, Lassen AT, Jensen CM, Coyne E, Dieperink KB. How to improve emergency care to adults discharged within 24 hours? Acute Care planning in Emergency departments (The ACE study): a protocol of a participatory design study *BMJ Open* 2020;**10:**e041743. doi: 10.1136/bmjopen-2020-041743

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References

1.   Forero, R., et al., *Perceptions and experiences of emergency department staff during the implementation of the four-hour rule/national emergency access target policy in Australia: a qualitative social dynamic perspective.* BMC Health Serv Res, 2019. **19**(1): p. 82.

2.   Sundhedsstyrelsen, Danske Regioner, and Sundheds og Ældreministeriet, *De danske akutmodtagelser. Statusrapport 2016*. 2017.

3.   Han, C.Y., A. Barnard, and H. Chapman, *Discharge planning in the emergency department: a comprehensive approach.* J Emerg Nurs, 2009. **35**(6): p. 525-7.

4.   Nielsen, L., et al., *Returning to everyday life after discharge from a short-stay unit at the Emergency Department-a qualitative study of elderly patients' experiences.* Int J Qual Stud Health Well-being, 2019. **14**(1): p. 1563428.

5.   Stevens, L., et al., *Fast track patients' satisfaction, compliance and confidence with emergency department discharge planning.* Australas Emerg Care, 2019. **22**(2): p. 87-91.

6.   Vaillancourt, S., et al., *Patients' Perspectives on Outcomes of Care After Discharge From the Emergency Department: A Qualitative Study.* Ann Emerg Med, 2017. **70**(5): p. 648-658.e2.

7.   Kremers, M.N.T., et al., *Patient's perspective on improving the quality of acute medical care: determining patient reported outcomes.* BMJ Open Qual, 2019. **8**(3): p. e000736.

8.   Lisby, M., et al., *Clinical impact of a comprehensive nurse-led discharge intervention on patients being discharged home from an acute medical unit: Randomised controlled trial.* Int J Nurs Stud, 2019. **100**: p. 103411.

9.   Levine, D.M., et al., *Hospital-Level Care at Home for Acutely Ill Adults: A Randomized Controlled Trial.* Ann Intern Med, 2020. **172**(2): p. 77-85.

10.   Johannessen, A.K. and S. Steihaug, *Municipal Acute Units as Part of the Clinical Pathway for Older Patients.* Int J Integr Care, 2019. **19**(4): p. 2.

11.   Hoffmann, E. and P.R. Olsen, *Like an ace up the sleeve: an interview study of nurses' experiences of the contact with relatives in a somatic emergency ward.* Scand J Caring Sci, 2018. **32**(3): p. 1207-1214.

12.   Elmqvist, C. and C. Frank, *Patients' strategies to deal with their situation at an emergency department.* Scand J Caring Sci, 2015. **29**(1): p. 145-51.

13.   Mackie, B.R., A. Marshall, and M. Mitchell, *Acute care nurses' views on family participation and collaboration in fundamental care.* J Clin Nurs, 2018. **27**(11-12): p. 2346-2359.

14.   Mackie, B.R., M. Mitchell, and A.P. Marshall, *Patient and family members' perceptions of family participation in care on acute care wards.* Scand J Caring Sci, 2018.

15.   Demidenko, J., et al., *Family functioning evaluated by family members of older patients and nurses in emergency departments.* Scand J Caring Sci, 2018. **32**(3): p. 1064-1073.

16.   Cetin-Sahin, D., et al., *Experiences of an Emergency Department Visit Among Older Adults and Their Families: Qualitative Findings From a Mixed-Methods Study.* J Patient Exp, 2020. **7**(3): p. 346-356.

17. Hsiao, P.R., et al., *Family needs of critically ill patients in the emergency department.* Int Emerg Nurs, 2017. **30**: p. 3-8.

18. Curran, J., et al., *Patient and caregiver expectations of emergency department care: A scoping literature review.* Int Emerg Nurs, 2017. **32**: p. 62-69.

19. Simonsen, J. and T. Robertson, *Routledge international handbook of participatory design*. 2012: Routledge.

20. Clemensen, J., et al., *Participatory design methods in telemedicine research.* J Telemed Telecare, 2017. **23**(9): p. 780-785.

21. Østervang, C., et al., *How to improve emergency care to adults discharged within 24 hours? Acute Care planning in Emergency departments (The ACE study): a protocol of a participatory design study.* BMJ Open, 2020. **10**(12): p. e041743.

22. Tong, A., P. Sainsbury, and J. Craig, *Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups.* Int J Qual Health Care, 2007. **19**(6): p. 349-57.

23. DEPT. *User Manuel Danish Emergency Process Triage - DEPT.* [cited 2021 02.07.2021]; Available from: http://deptriage.dk/brugervejledning/.

24. Moser, A. and I. Korstjens, *Series: Practical guidance to qualitative research. Part 3: Sampling, data collection and analysis.* Eur J Gen Pract, 2018. **24**(1): p. 9-18.

25. Green, J. and N. Thorogood, *Qualitative methods for health research.* . 3rd edition. ed. 2014: Sage. .

26. Abalos, E.E., et al., *Husserlian Phenomenology and Colaizzi's Method of Data Analysis: Exemplar in Qualitative Nursing Inquiry Using Nursing As Caring Theory.* International journal for human caring, 2016. **20**(1): p. 19-23.

27. Spradley, J., *Participant Observation*. 2016, Long Grove, : waveland Press.

28. Kvale S and Brinkmann S, *Interview: introduktion til et håndværk.* . 2009, Kbh.: Hans Reitzel.

29. Malterud K, *Kvalitative metoder i medisinsk forskning*. 2014, Osla: Univeristetsforlaget.

30. Sykepleiernes Samarbeid i Norden Northern Nurses Federation, *Ethical guidelines for nursing research in the Nordic countries.* 2003.

31. Bittencourt, R.J., et al., *Interventions in overcrowding of emergency departments: an overview of systematic reviews.* Rev Saude Publica, 2020. **54**: p. 66.

32. De Freitas, L., et al., *Interventions to improve patient flow in emergency departments: an umbrella review.* Emerg Med J, 2018. **35**(10): p. 626-637.

33. Rising, K.L., et al., *Development of the Uncertainty Communication Checklist: A Patient-Centered Approach to Patient Discharge From the Emergency Department.* Acad Med, 2020. **95**(7): p. 1026-1034.

34. Samuels-Kalow, M., et al., *Unmet Needs at the Time of Emergency Department Discharge.* Acad Emerg Med, 2016. **23**(3): p. 279-87.

35. Samuels-Kalow, M.E., A.M. Stack, and S.C. Porter, *Effective discharge communication in the emergency department.* Ann Emerg Med, 2012. **60**(2): p. 152-9.

36. Rising, K.L., et al., *"I'm Just a Patient": Fear and Uncertainty as Drivers of Emergency Department Use in Patients With Chronic Disease.* Ann Emerg Med, 2016. **68**(5): p. 536-543.

37. Graham, B., et al., *'They do not care how much you know until they know how much you care': a qualitative meta-synthesis of patient experience in the emergency department.* Emerg Med J, 2019. **36**(6): p. 355-363.

38. Jensen, C.M., et al., *Empowerment of whom? The gap between what the system provides and patient needs in hip fracture management: A healthcare professionals' lifeworld perspective.* Int J Orthop Trauma Nurs, 2020. **38**: p. 100778.

39. Barreto, M.D.S., et al., *Meanings attributed by family and patients to family presence in emergency rooms.* Rev Bras Enferm, 2019. **72**(6): p. 1684-1691.

40. Forsgarde, E.S., M. From Attebring, and C. Elmqvist, *Powerlessness: Dissatisfied patients' and relatives' experience of their emergency department visit.* Int Emerg Nurs, 2016. **25**: p. 32-6.

41. Naef, R., et al., *Implementing Family Systems Care Through an Educational Intervention With Nurses and Midwives in Obstetrics and Gynecological Care: A Mixed-Methods Evaluation.* J Fam Nurs, 2020. **26**(2): p. 138-152.

42. Wright, L.M. and M. Leahey, *Maximizing time, minimizing suffering: The 15-minute (or less) family interview. .* Journal of Family Nursing, 1999. **5(3),**: p. 259-274.

43. Emmamally, W., C. Erlingsson, and P. Brysiewicz, *Partnering with families: Is the ED ready?* Int Emerg Nurs, 2019. **42**: p. 1.

44. Korstjens, I. and A. Moser, *Series: Practical guidance to qualitative research. Part 4: Trustworthiness and publishing.* Eur J Gen Pract, 2018. **24**(1): p. 120-124.

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the inter view or focus group?	
Duration	21	What was the duration of the inter views or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

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What are the needs and preferences of patients and family members discharged from the emergency department within 24 hours? A qualitative study towards a family-centred approach

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Title

What are the needs and preferences of patients and family members discharged from the emergency department within 24 hours? A qualitative study towards a family-centred approach

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Abstract

Objective: There is an increase in patients being discharged after short stays in the emergency department, but there is limited knowledge of their perspectives on treatment and care. This study aims to explore and understand the needs and preferences of emergency care from the perspective of patients and family members discharged from the emergency department within 24 hours of admission.

Design: The study reports from the first phase in an overall Participatory design project. Systematic text condensation was used to identify key themes from field observations and interviews with patients and family members.

Setting: This study was conducted in two emergency departments in the Region of Southern Denmark.

Participants: All adults aged ≥18 years who had been discharged from the emergency department within 24 hours were eligible to take part. Purposeful sampling was used to recruit patients and family members with different sociodemographic features.

Results: Field observational studies (n=50 hours), individual interviews with patients (N=19) and family members (N=3), and joint interviews with patients and family members (N=4) were carried out. Four themes were derived from the material: 1) being in a vulnerable place— having emotional concerns; 2) having a need for person-centred information; 3) the atmosphere in the emergency department; and 4) implications of family presence.

Conclusion: This study demonstrates a gap between patients' and family members' needs and preferences and what current emergency departments deliver. The findings highlight the importance of family and person-centred care. Tailored communication and information with genuine involvement of family members is found to be essential needs during acute illness.

Strengths and limitations

- o The findings and methodological approaches in the study have been critically evaluated and discussed by experienced researchers from different fields of research.
- o Data were generated using different methods and involved a broad representation of participants to ensure robust findings.
- o Quotations support the trustworthiness of the findings.
- o Although there is a thorough description of the research process to support credibility, descriptions of the findings are contextual and reflect a Danish context.

Introduction

Internationally, many countries comparable to Denmark, such as the United Kingdom and Australia, work to establish an organisational structure in emergency departments (ED) to prevent overcrowding and access blockage [1]. A four-hour rule was introduced in EDs for practitioners to develop a plan of treatment: either admission or discharge was expected within four hours [1]. Across 21 Danish EDs, the same structure exists to promote clinical assessment and treatment plans of patients within four hours, a short stay in a Danish ED typically range from <4 - 48 hours [2]. However, a lack of thoroughness in the delivery of information and assessment of patients' and family members' individual needs may result in patients being discharged from the ED who are unable to maintain their health status [3, 4]. The environment in EDs is challenging, with a diversity of health needs to be met [5]. Key concerns were identified by patients including, understanding their condition, symptom relief, reassurance and a treatment plan [6, 7]. However, the focus was on patient-reported measures to improve acute care and did not include the family perspective [6, 7]. Interventions related to patient outcomes are limited or focus on reducing re-admission rather than satisfying needs and preferences [8].

Globally, many initiatives focus on out-of-hospital care, such as hospital at home, telehealth and outpatient clinics to support ongoing treatment initiated in the hospital as well to support early discharge [9, 10]. In this care, family members play an active role in maintaining patient outcomes after early discharge to homes [11, 12]. Mackie et al. found

in a qualitative study that health professionals identified the advantage of family participation in care for enhancing the quality of care and improving patient satisfaction [13, 14]. However, research on the needs of family members involved in short visits to EDs is sparse or focuses on elderly patients [15, 16]. To date, little is known of how patients and families experience short-term stays in the ED and what needs and preferences they have [17, 18]. In the interest of organising and practicing tailored care, it is essential to explore the needs and preferences of patients and their family members to ensure that the care provided is valuable.

Objective

This study aims to explore and understand the needs and preferences of emergency care from the perspective of patients and family members discharged from the Emergency department within 24 hours of admission.

Methods

Study design

Participatory design (PD) is this study's overall research methodology [19]. PD has a phenomenological and hermeneutical stance using qualitative methods to understand lived experiences and needs of individuals[19, 20]. As methods, field observations and interviews with patients and family members were chosen. This study reports from the first phase of a three-phased PD- project [21].Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups were used as guidelines[22].

Patient involvement

The local patient and family member council have read the study protocol and gave suggestions for improvements e.g., regarding sampling strategy and clarity of the patient population included in the study.

Setting

The study was conducted in EDs at two hospitals in the Region of Southern Denmark:

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1) Odense University Hospital (OUH), a 1,000-bed university hospital that covers all specialties. The ED has 69,000 annual attendees. On average, 32 patients are admitted per day, and 50% are discharged within 24 hours.

2) The Department of Emergency Medicine, Hospital of Lillebaelt, Kolding. The Hospital of Kolding has 320 beds. The ED has 50,000 annual attendees and receives 146 patients per day. Visitor restrictions due to Covid-19 were in place in 2020, and only one family member per patient was allowed to accompany the patient in the ED.

Participants

Eligibility criteria: Patients were Danish-speaking individuals ≥ 18 years old with a medical or surgical diagnosis who had been discharged from the ED after less than 24 hours. Family members accepted by the patient were included.

Exclusion criteria: Patients with cognitive impairment as evaluated by an individual clinical judgement according to their ability to comprehend the terms of participating were excluded. Patient triaged at the highest and lowest triage level as per the Danish Emergency Process Triage were excluded [23]. The highest triage level is received care in trauma room and not expected to be discharged within 24 hours. The lowest triage level is received care for minor cut or concern by either a nurse or a physician with no examinations.

Sample size: The minimum sample was 20 patients. Data collection continued until thematic saturation [24] and a pre-defined target group obtained (table 1). No specific target sample was set for family members. Features were defined by the research group to ensure diversity represented.

Patients (n=20)	
Age	10 patients ≥65 years of age
	10 patients ≤65 years of age
Sex	10 females
	10 males
Symptoms	10 patients having surgical symptoms
	10 patients medical symptoms

Education level	10 patients with education level above secondary school 10 patients with education level below secondary school
Function level	10 patients receiving primary care 10 patients not receiving primary care
Social status	10 living on their own in independent accommodation 10 living together with someone
Frequency of stay	10 having their first visit in the ED 10 having more than one visit in the ED

Table 1: Patient features representing the target group population.

Data collection

Data collection was carried out by CØ, who has thirteen years of experience in nursing and holds a Master of Science in Nursing. She had no care responsibilities for any of the patients admitted to the ED.

Researcher characteristics and reflexivity

A phenomenological-hermeneutical approach allowed CØ to recognize her perceptions as an experienced emergency nurse within hermeneutic interpretation [25]. To enable recognition of the researchers preconceived ideas CØ wrote down her preunderstanding of why patients lack information being discharged and might have many concerns[26]. This reflection provided an initial focus for research questions [26].

Recruitment

Eligible patients and their family members were purposively recruited between August 9th and October 29th 2020, by the first author (CØ). In both EDs a nurse coordinator keeps an overview of available rooms, in and out hospital transfers and expected length of stay for each patient in close collaboration with the emergency physicians. CØ discussed the target group population with the nurse coordinator to identify potential participants. No time restriction related to how long the patients had stayed in the ED was set besides a criterion of discharge before 24 hours of admission. If the patient was not discharged as expected they were excluded from the study. After identifying a potential participant CØ

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talked to the nurses who provided the care and they asked for the patient's permission for CØ to approach the patient. If accepted, CØ informed the patient and/or family members orally and in writing about the study. At the end of the observation all participants were asked for consent for one interview within the first week after discharge.

Field observational studies

Field observations helped the authors to understand how the interactions and activities in the ED informed experiences, needs and preferences [25]. Furthermore, it provided first-hand knowledge of consistency between what actually happened during the participants interaction with health professionals in emergency and what was said by participants in the interviews[25]. Inspired by Spradley's nine dimensions, [27] an observational guide was designed and pilot-tested in two cases. The observational guide contained several points including human interactions, time and events in the ED. CØ was present at the EDs for three to six hours per day, during both morning and evening shifts, and made observations in medical and surgical areas. CØ followed the patients during their stay joining them in the hospital room, examinations and other areas the participant required treatment. Duration of the observations varied in respect for the patient's wishes from 30 minutes to 4 hours. Field notes were written each day containing observations and quotes.

Interviews

To gain an understanding of the needs and preferences interviews extended the observation data. Both individual and joint interviews were utilised, as the study aimed to explore both the perspectives of the patients and family members as well as their joined needs. The authors wanted to give the participants the power to decide which interview style they preferred. Therefore, interviews were conducted as face-to-face, telephone, individual or joint interviews according to participant preference and to accommodate the Covid-19 induced restrictions. All interviews were conducted using an interview guide inspired by Kvale and Brinkmann [28], recorded and transcribed. The guide was developed based on the identified scientific literature on the topic and the preliminary results of field observations. An example of an interview question is: "What significance does family have in your lives?"

Data from the observations were used directly in the interview e.g. "At the end of the stay you talked to a nurse, can you tell me about that experience?"

At the end of the interview, the interviewer summarized the interview and checked with the participant to ensure correct interpretation. Participants were asked if they would like to read the transcript. Two participants accepted with no further comments. The interview guide was pilot tested with two cases. Interviews were conducted one time, two to seven days after discharge.

Analysis

The analysis was performed according to systematic text condensations four steps [29]. An overall caption was initially made of the data to extract dominant themes. This was followed by dividing dominant themes into meaningful topics. Finally, the data were coded to put meaningful topics into categories. Field observational data were used to support interview data. The data from field observations and the interviews were analysed separately and then combined across the participant interaction to understand the deeper aspects of health professional interchanges with participants and the participants recollection of the interaction and information. After this process all data were synthesized. CØ was in charge of the coding process. During the coding process the author group met to discuss the codes as strategy to mitigate potential bias. Credibility

was also enhanced by the analysis being conducted using investigator triangulation, as data were continuously discussed with all co-authors. NVivo12 was used to store, code and systematise data.

Ethics

In accordance with the Helsinki Declaration and the Ethical Guidelines for Nursing Research [30], participants were asked both orally and in writing to grant consent. According to Danish legislation, this study did not need ethical approval from the National Committee on Health Research Ethics (REF: S-20192000-111). The study is registered with the 'Record of data process of Registry of Southern Denmark' (19/22672). Data were stored in SharePoint (Microsoft Corporation) AND OPEN_938.

Results

Participant descriptions

Field observational studies were conducted for 20 days (50 hours total; August to October 2020). Twenty-eight patients were asked permission to participate in the study, and four declined due to mental distress. Twenty-four patients accepted participation (Table 2); however, one patient did not respond to the telephone call. Seven family members accepted (Table 3). Nineteen individual interviews were conducted with patients, three with individual family members and four as joint interviews patient and family. To achieve enrollment across all target groups, recruitment continued until 24 patients were enrolled. Interviews were conducted at a convenient location for the patient and/or family, either by telephone (n=23) or at the patient's home (n=3).

Patient characteristics	N (%)
Gender *Male* *Female*	9 (37.5) 15 (62.5)
Age *1 –35* *36–49* *50–65* *66–80*	3 (12.5) 5 (20.8) 5 (20.8) 6 (25.0) 5 (20.8)

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81 or older	
Living situation *Living alone* *Living with others*	11 (45.8) 13 (54.2)
Nationalities represented in the study	4 (100)
Education level *Below secondary school* *Above secondary school*	11 (45.8) 13 (54.2)
Function level *Receives primary homecare* *No help needed*	9 (37.5) 15 (62.5)
Method of admittance *By ambulance* *Attending the ED alone* *Attending the ED with family members*	15 (62.5) 5 (20.8) 4 (16.7)
Family in the ED *Yes* *No*	13 (54.2) 11 (45.8)
Frequency of stay *First time in ED* *More than one visit in the ED*	9 (37.5) 15 (62.5)
Main symptoms *Medical* *Surgical* *Neurological* *Orthopedic* *Gynecological*	10 (41.7) 6 (25.0) 3 (12.5) 4 (16.7) 1 (4.2)
Co-morbidity *Yes* *No*	13 (54.2) 11 (45.8)

Table 2: Characteristics of participating patients.

Family member characteristics	N (%)
Gender *Male* *Female*	4 3
Mean age (years)	55
Family relation to patient *Daughter* *Son* *Spouse* *Parent*	1 1 4 1

Education level	
Below secondary school	3
Above secondary school	4

Table 3: Characteristics of participating family members.

Four themes were developed:

1. Being in a vulnerable place— having emotional concerns

2. Having a need for person-centred information

3. The atmosphere in the emergency department

4. The implications of family involvement

Being in a vulnerable place—having emotional concerns

Most of the patients expressed a sense of vulnerability while attending the ED. Some patients had been to the ED several times, but that did not necessarily make them more confident. Patients described feelings such as stress, anxiety and being afraid of what was going to happen. Only a few patients shared their emotional thoughts with HCPs. Both patients and family members highlighted that they had the need for an approach that showed an understanding of their emotional concerns alongside physical symptoms.

> *I was admitted late in the evening yesterday. It is my third time here… Actually, I have been terrified since last time… You know, psychologically scared… (Informal interview during field observation, female patient in her 60s).*

Similar for patients and family members was the need for clear signals from HCPs. When finding themselves in such a stressful and tense situation, they wanted HCPs to navigate them through their stay in the ED by being precise and direct when communicating. Patients described the need for knowing what they were waiting for, as otherwise, unproductive thoughts about being severely ill came to their minds in addition to feelings of being forgotten by HCPs.

> *Waiting time is hard… You do not know what is happening, and you speculate if they (HCPs) soon will find out…. I am all alone with my thoughts (female patient in her 80s).*

The majority of the patients underlined that the stay in the ED was only a small part of their trajectory; the time before attending the ED could have been very exhausting, and the time after discharge was filled with concerns or doubt related to the progress of the illness, new medication, and follow-ups.

> *She talks in the phone. She says that no one asked if she was able to handle things at home. "But I need home care, how do we do this?" she asked her family during the phone conversation (fieldnote, October 2020).*

Patients expressed that they were in a blurry state of mind, not able to remember details when returning to home. They preferred a follow up at their general practitioner, looking into the electronic record app from home or having family to help them remember elements in the treatment plan after discharge. Even if nurses and physicians strived to be thorough in communicating discharge information, patients seemed not to be able to remember things such as where to go for follow-up, what to do if they started feeling worse, future treatment plans, or how to manage new medication.

> *The physician is having a long conversation with him. Pleasant atmosphere. They both smile. They have eye contact. They agree on the plan of discharge (fieldnote, August 2020).*
> *I only remember that I was not allowed to drive, but actually I do not know for how long? (Patient talking about his experience reflected in the fieldnote, male in this 60s).*

Some patients explained that they had information overload in a very short period of time, and in relation to finding themselves in an unbalanced situation, they could not process as much as they normally would be able to. There was no difference in this sense across different ages. Family members did not describe the same issues.

> *At that time, I did not realise, I had to ask when and how I should take the new medication... I had to call the ED the day after (female patient in her 40s).*

Having a need for person-centred information

Both patients and family members emphasised a desire for more information. Especially, the patients preferred having things repeated frequently in plain language. Moreover, the uncertainty of being acutely ill seemed to intensify a need for knowing when changes in the treatment plan are made. Both patients and family members would have preferred a system where they could follow 'live' updates of the journal.

> *The patient and her husband talk about wanting access to the electronic journal while we are in the hospital (fieldnote, September 2020).*

The participants expressed understanding of the limited time available to provide information when the department was busy but underlined that their need for information was still valid.

> *There I was, about to explode. I kept myself in control and asked if anyone had thought about telling ME about the changes in the plan. I had waited for eight hours, and I was apparently the only one who did not know that the planned examination was changed (female patient in her 30s).*

Those patients who found their information needs fulfilled described that HCPs had resources to collect the patient-reported data, listen to the patient in a genuine way, and inform them about expected examinations at the same time.

> *When the pictures from the scan were ready, the physician sat beside me and commented on them in a way that I could understand. It could not have been done better (male patient in his 80s).*

Experiences that helped patients and family members alleviate their burdens were related to information and communication levels. Patients preferred communication from HCPs to be provided in a clear and concise way. Lack of confidence from the HCP negatively affected how patients were able to deal with their situations.

The insecurity the physician came in with… He was so shy and cautious… In this situation, I had the need for him to step forward and say: 'We are going to do this and this… and we have everything in control.' He failed to relieve the stress I was carrying on my shoulders (male patient in his 50s).

Being chronically ill appeared to present diverse information needs. Family members and patients dealing with chronic disease expressed a need for HCPs to listen to them and plan a treatment linked to their previous experiences. Patients preferred to see experienced nurses and physicians being able to handle symptoms and begin treatment without the need for consulting more experienced colleagues.

It is like they follow a manual instead of listening to me. Sometimes I just take the medication they always offer, even though I know, and have told them many times, that it does not take away MY pain (female patient in her 40s).

The atmosphere in emergency departments

Aspects of a 'busy environment' were mentioned by all participants. Situations where patients were discharged by the physician but still waited for details on things like medications delayed them leaving the hospital. The patients described an uncomfortable sense of disturbing the nurse, as they knew they were busy, but on the other hand, they saw possibilities of making room for new patients if they just were given the details needed.

She looks at me and says: why is she (the nurse) not coming as we agreed to…should I call for her again…. Maybe she gets angry with me…. She calls for the nurse again (fieldnote, September 2020).

Being a patient in a busy environment provided insecurity if HCPs did not share which examinations were initiated, what the progress on these was, and what the estimated time was before a treatment plan could be formed. They found themselves trapped in a worrying situation with no options to find answers to clarify their speculations. Better clarity of the progress was primary preferred by the patients.

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I tried many times to find out if the scan was booked. No one wanted to say anything… I know there must be some priority lists, but where I am on that? No one seemed to want to talk to me... I just wanted an estimate of how long it would take… That uncertainty—I really hope the time spent being uncertain could be reduced (male patient in his 50s).

The participants highlighted how the HCPs' attitudes influenced how their needs were fulfilled, describing an ideal connection with the HCP as involving being seen as a person rather than 'just another patient in the row'. Negative attitudes also seemed to affect the time after discharge, as it entailed a need for processing the experience through conversation and discussion of the encounter.

It was frustrating that the physician, a new one, came to send us home… He started to complain about how this was not his intended job, as he worked in another area of the hospital… That was frustrating to be met in that way and we talked a lot about his attitude after returning to home (husband in his 40s).

Implications of family involvement

The participants explained that family presence in EDs provided support. Often, patients found themselves in a position where it was difficult to explain and keep track of details of what had happened before the acute symptoms occurred, and family members were able to provide those details.

I was pretty blurry, but my husband could tell them (HCP) about the past days, the operation and so on; that made me calm (female patient in her 50s).

Family members of patients who had been in the ED many times could feel great frustration when their loved ones were discharged rapidly without any interventions or further treatment plans. They described a feeling of powerlessness without any means to affect the way forward, and they asked for a clear treatment plan or symptom control.

One time I went with her… I thought, now I really had to tell them… But I could not do anything… Nothing helped… We were sent home as all the other times (husband in his 40s).

In many cases, family members played a central role after discharge. The patients who did not have family members nearby arranged for supportive telephone calls from neighbors or primary homecare. In some instances, the nurses in the ED recognised the patient's need for extra support after discharge, but this was the result of individual judgments by the nurses.

A nurse enters the hospital room, she tells the patient that she has tried to reach the primary homecare by phone but did not succeed. She asks if the patient could call them herself when she comes home (fieldnote, October 2020).

Family members described a need to be heard and genuinely involved in discharge plans and patients preferred if they had family they would like to involve. Family members who were not able to be physically present during the emergency admission stressed that they would like to be included in discussions regardless.

They did not listen to me; it was way too soon (to discharge). When we came home, it got worse. I couldn't even get her to the bathroom. I called 112 again, I couldn't handle the situation (son in his 50s).

Discussion

Principal findings

We investigated the needs and preferences of patients discharged from the ED and their family members and found that they wanted health professionals to understand their vulnerability. They also preferred HCPs to engage in direct communication that was tailored to their level of understanding—especially information on waiting times and treatment plans. The busy environment caused doubts about control of their treatment plan and provided feelings of being 'just another patient' in the line. No specific strategy for including family in the interactions with health professionals was observed, however, a need for genuine family involvement in discharge plans was identified.

A gap between needs and organisation

Research has explored interventions to reduce overcrowding in the ED, placing a focus on patient flow and effective organisation [31, 32]. These changes might have a psychosocial cost, however, as we identified a gap between the needs of patients and family members and what the healthcare system currently delivers. Patients have several unmet needs, including information and psychosocial support during a time of vulnerability. A need for clear communication has also been found in previous research [33-35]. A protocol for discharge communication in the ED, could support and train HCPs to possess person-centred communication skills [33]. Moreover, implementing a "protected and undisturbed time" for HCPs when entering a discharge conversation [34]. This could be a possible solution to reduce the gap between an effective and flow-focused environment and the need for clear communication. Patients reported difficulties remembering the provided information. Lack of recall caused patients to contact the ED, see their general practitioner or look at the electronic record app to understand instructions. Interventions to improve patient understanding after discharge were previously initiated in a qualitative American study, which suggested that patients follow up at home and revisit information [36]. However, these findings differ from a Danish randomised study by Lisby et al., which explored services such as telephone follow-up and discharge letters [8]. They found that telephone follow-up did not show a significant effect on patients' experiences of discharge [8]. These interventions did not seem to reduce the gap between patient needs and what the current health care system is able to deliver.

A main finding in our study was the need to identify the vulnerability of the patients and family. Therefore, we suggest that future interventions include tailored communication and a person-centred approach based on an understanding of the underlying sense of vulnerability acute patients and family members suffer from. Vaillancourt et al. 2017 developed a conceptual model of ED care in which they found that patients have a need for HCPs to recognise their emotional worries [6]. A meta-synthesis on ED patient experience found that the ED information must be tailored to patients if their emotional needs are to be met [37]. They emphasised a request for knowledge about 'patient

suffering' from anxiety and fear in the ED and its implications [37]. In parallel, a Danish study exploring hip-facture management also identified a gap between what the healthcare system provides, and patients' needs when they are in a shock-like state of mind [38]. Similar to our findings, they stressed a need for more individual targeted means of informing and educating patients to meet their needs [38].

Therefore, our findings create an awareness of the vulnerable state of mind acute patients possess. From this knowledge, the feasibility of developing future interventions to accommodate needs in the ED might be improved.

A need for genuine family involvement in the ED

Family members in our study described a need for genuine involvement and recognition by HCPs. Family members play a central role during a patient's illness. They help patients 'translate' care and need to be included in treatment and care planning. Similar research has reported that family members are recognised as a resource in the ED [11, 39]. Family members can assist with practical and emotional support, but direct involvement in care is lacking, especially in busy periods [11, 40].

A lack of genuine involvement was also identified in our study, resulting in frustrations and feelings of powerlessness. Our findings highlight that for family members to be a resource, they need to be involved in discussions to ensure fundamental details related to the patient course of treatment are not missed, leading to readmission. To promote genuine family involvement in care, a systematic approach towards family inclusion should be introduced and HCPs trained in family-focused communication [41, 42]. Genuine involvement with families might reduce the uncertainty associated with the illness experience and increase the ability to self-manage at home [43]. One strength of our study was the triangulation of patient and family member perspectives combined with field observations. This introduces a broad perspective into the research. The inclusion of two sites with no notable differences in participants' statements further strengthens the validity of the findings. The study constitutes an important and crucial step towards an understanding of how to design interventions to improve family-centred

care. The next phase of this three-phased study will be a co-design development of an intervention to meet the needs of patients and family members.

Limitations

Data collection by a single researcher was a potential bias but also ensured reliability in data collection. An observational guide and a systematic analysis process was followed to reduce the risk of bias [44]. Moreover, methodological and investigator triangulation were applied to support credibility [44]. Telephone interviews prevented the interviewer from seeing facial expressions and body language, which reduced the ability to clarify answers if uncertainty [28]. Only family members at the hospital were recruited, leading to a small sample size and also potential selection bias. Having a strategy for recruiting family members not physically present in the hospital might have given a broader aspect into the family perspectives. For future research similarities and differences in the needs of patients and family members could create a broader understanding of emergency care. Furthermore, we did not include patients with cognitive impairment due to the complexity of the patient category; this is suggested for future research.

Conclusion

This study demonstrates that there is a gap between the needs and preferences of patients and family members and what the emergency department delivers. The findings highlight patient and family members need an increased understanding on them being in a vulnerable state of mind. They have a need for person-centred information with genuine involvement of family members.

Table labels:

Table 1: Patient features representing the target group population.

Table 2: Participant characteristics of patients.

Table 3: Participant characteristics of family members.

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Competing interests: There are no competing interests**.**

Author contribution: CMJ, KBD, EC, ATL and CØ designed the study. CØ collected data. CMJ, KBD, and CØ performed the analysis. CØ took the lead in drafting the manuscript; all authors commented and gave feedback. All authors approved the final version of the manuscript.

Patient consent: Consent was obtained from all patients.

Data sharing statement: Data can be shared on reasonable request.

Supplementary file: The study protocol can be accessed: Østervang C, Lassen AT, Jensen CM, Coyne E, Dieperink KB. How to improve emergency care to adults discharged within 24 hours? Acute Care planning in Emergency departments (The ACE study): a protocol of a participatory design study *BMJ Open* 2020;**10:**e041743. doi: 10.1136/bmjopen-2020-041743

References

1.   Forero, R., et al., *Perceptions and experiences of emergency department staff during the implementation of the four-hour rule/national emergency access target policy in Australia: a qualitative social dynamic perspective.* BMC Health Serv Res, 2019. **19**(1): p. 82.

2.   Sundhedsstyrelsen, Danske Regioner, and Sundheds og Ældreministeriet, *De danske akutmodtagelser. Statusrapport 2016*. 2017.

3.   Han, C.Y., A. Barnard, and H. Chapman, *Discharge planning in the emergency department: a comprehensive approach.* J Emerg Nurs, 2009. **35**(6): p. 525-7.

4.   Nielsen, L., et al., *Returning to everyday life after discharge from a short-stay unit at the Emergency Department-a qualitative study of elderly patients' experiences.* Int J Qual Stud Health Well-being, 2019. **14**(1): p. 1563428.

5.   Stevens, L., et al., *Fast track patients' satisfaction, compliance and confidence with emergency department discharge planning.* Australas Emerg Care, 2019. **22**(2): p. 87-91.

6.   Vaillancourt, S., et al., *Patients' Perspectives on Outcomes of Care After Discharge From the Emergency Department: A Qualitative Study.* Ann Emerg Med, 2017. **70**(5): p. 648-658.e2.

7.   Kremers, M.N.T., et al., *Patient's perspective on improving the quality of acute medical care: determining patient reported outcomes.* BMJ Open Qual, 2019. **8**(3): p. e000736.

8.   Lisby, M., et al., *Clinical impact of a comprehensive nurse-led discharge intervention on patients being discharged home from an acute medical unit: Randomised controlled trial.* Int J Nurs Stud, 2019. **100**: p. 103411.

9.   Levine, D.M., et al., *Hospital-Level Care at Home for Acutely Ill Adults: A Randomized Controlled Trial.* Ann Intern Med, 2020. **172**(2): p. 77-85.

10.   Johannessen, A.K. and S. Steihaug, *Municipal Acute Units as Part of the Clinical Pathway for Older Patients.* Int J Integr Care, 2019. **19**(4): p. 2.

11.   Hoffmann, E. and P.R. Olsen, *Like an ace up the sleeve: an interview study of nurses' experiences of the contact with relatives in a somatic emergency ward.* Scand J Caring Sci, 2018. **32**(3): p. 1207-1214.

12.   Elmqvist, C. and C. Frank, *Patients' strategies to deal with their situation at an emergency department.* Scand J Caring Sci, 2015. **29**(1): p. 145-51.

13.   Mackie, B.R., A. Marshall, and M. Mitchell, *Acute care nurses' views on family participation and collaboration in fundamental care.* J Clin Nurs, 2018. **27**(11-12): p. 2346-2359.

14.   Mackie, B.R., M. Mitchell, and A.P. Marshall, *Patient and family members' perceptions of family participation in care on acute care wards.* Scand J Caring Sci, 2018.

15.   Demidenko, J., et al., *Family functioning evaluated by family members of older patients and nurses in emergency departments.* Scand J Caring Sci, 2018. **32**(3): p. 1064-1073.

16.   Cetin-Sahin, D., et al., *Experiences of an Emergency Department Visit Among Older Adults and Their Families: Qualitative Findings From a Mixed-Methods Study.* J Patient Exp, 2020. **7**(3): p. 346-356.

17. Hsiao, P.R., et al., *Family needs of critically ill patients in the emergency department.* Int Emerg Nurs, 2017. **30**: p. 3-8.

18. Curran, J., et al., *Patient and caregiver expectations of emergency department care: A scoping literature review.* Int Emerg Nurs, 2017. **32**: p. 62-69.

19. Simonsen, J. and T. Robertson, *Routledge international handbook of participatory design*. 2012: Routledge.

20. Clemensen, J., et al., *Participatory design methods in telemedicine research.* J Telemed Telecare, 2017. **23**(9): p. 780-785.

21. Østervang, C., et al., *How to improve emergency care to adults discharged within 24 hours? Acute Care planning in Emergency departments (The ACE study): a protocol of a participatory design study.* BMJ Open, 2020. **10**(12): p. e041743.

22. Tong, A., P. Sainsbury, and J. Craig, *Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups.* Int J Qual Health Care, 2007. **19**(6): p. 349-57.

23. DEPT. *User Manuel Danish Emergency Process Triage - DEPT.* [cited 2021 02.07.2021]; Available from: http://deptriage.dk/brugervejledning/.

24. Moser, A. and I. Korstjens, *Series: Practical guidance to qualitative research. Part 3: Sampling, data collection and analysis.* Eur J Gen Pract, 2018. **24**(1): p. 9-18.

25. Green, J. and N. Thorogood, *Qualitative methods for health research. .* 3rd edition. ed. 2014: Sage. .

26. Abalos, E.E., et al., *Husserlian Phenomenology and Colaizzi's Method of Data Analysis: Exemplar in Qualitative Nursing Inquiry Using Nursing As Caring Theory.* International journal for human caring, 2016. **20**(1): p. 19-23.

27. Spradley, J., *Participant Observation*. 2016, Long Grove, : waveland Press.

28. Kvale S and Brinkmann S, *Interview: introduktion til et håndværk. .* 2009, Kbh.: Hans Reitzel.

29. Malterud K, *Kvalitative metoder i medisinsk forskning*. 2014, Osla: Univeristetsforlaget.

30. Sykepleiernes Samarbeid i Norden Northern Nurses Federation, *Ethical guidelines for nursing research in the Nordic countries.* 2003.

31. Bittencourt, R.J., et al., *Interventions in overcrowding of emergency departments: an overview of systematic reviews.* Rev Saude Publica, 2020. **54**: p. 66.

32. De Freitas, L., et al., *Interventions to improve patient flow in emergency departments: an umbrella review.* Emerg Med J, 2018. **35**(10): p. 626-637.

33. Rising, K.L., et al., *Development of the Uncertainty Communication Checklist: A Patient-Centered Approach to Patient Discharge From the Emergency Department.* Acad Med, 2020. **95**(7): p. 1026-1034.

34. Samuels-Kalow, M., et al., *Unmet Needs at the Time of Emergency Department Discharge.* Acad Emerg Med, 2016. **23**(3): p. 279-87.

35. Samuels-Kalow, M.E., A.M. Stack, and S.C. Porter, *Effective discharge communication in the emergency department.* Ann Emerg Med, 2012. **60**(2): p. 152-9.

36. Rising, K.L., et al., *"I'm Just a Patient": Fear and Uncertainty as Drivers of Emergency Department Use in Patients With Chronic Disease.* Ann Emerg Med, 2016. **68**(5): p. 536-543.

37. Graham, B., et al., *'They do not care how much you know until they know how much you care': a qualitative meta-synthesis of patient experience in the emergency department.* Emerg Med J, 2019. **36**(6): p. 355-363.

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38. Jensen, C.M., et al., *Empowerment of whom? The gap between what the system provides and patient needs in hip fracture management: A healthcare professionals' lifeworld perspective.* Int J Orthop Trauma Nurs, 2020. **38**: p. 100778.

39. Barreto, M.D.S., et al., *Meanings attributed by family and patients to family presence in emergency rooms.* Rev Bras Enferm, 2019. **72**(6): p. 1684-1691.

40. Forsgarde, E.S., M. From Attebring, and C. Elmqvist, *Powerlessness: Dissatisfied patients' and relatives' experience of their emergency department visit.* Int Emerg Nurs, 2016. **25**: p. 32-6.

41. Naef, R., et al., *Implementing Family Systems Care Through an Educational Intervention With Nurses and Midwives in Obstetrics and Gynecological Care: A Mixed-Methods Evaluation.* J Fam Nurs, 2020. **26**(2): p. 138-152.

42. Wright, L.M. and M. Leahey, *Maximizing time, minimizing suffering: The 15-minute (or less) family interview. .* Journal of Family Nursing, 1999. **5(3),**: p. 259-274.

43. Emmamally, W., C. Erlingsson, and P. Brysiewicz, *Partnering with families: Is the ED ready?* Int Emerg Nurs, 2019. **42**: p. 1.

44. Korstjens, I. and A. Moser, *Series: Practical guidance to qualitative research. Part 4: Trustworthiness and publishing.* Eur J Gen Pract, 2018. **24**(1): p. 120-124.

Protocol

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How to improve emergency care to adults discharged within 24 hours? Acute Care planning in Emergency departments (The ACE study): a protocol of a participatory design study

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ABSTRACT

Introduction The development of acute symptoms or changes in diseases led to feelings of fear and vulnerability and the need for health professional support. Therefore, the care provided in the acute medical and surgical areas of the emergency department (ED) is highly important as it influences the confidence of patients and families in managing everyday life after discharge. There is an increase in short-episode (<24 hours) hospital admissions, related to demographic changes and a focus on outpatient care. Clear discharge information and inclusion in treatment decisions increase the patient's and family's ability to understand and manage health needs after discharge, reduces the risk of readmission. This study aims to identify the needs for ED care and develop a solution to improve outcomes of patients discharged within 24 hours of admission.

Methods and analysis The study comprises the three phases of a participatory design (PD). Phase 1 aims to understand and identify patient and family needs when discharged within 24 hours of admission. A qualitative observational study will be conducted in two different EDs, followed by 20 joint interviews with patients and their families. Four focus group interviews with healthcare professionals will provide understanding of the short pathways. Findings from phase 1 will inform phase 2, which aims to develop a solution to improve patient outcomes. Three workshops gathering relevant stakeholders are arranged in the design plus development of a solution with specific outcomes. The solution will be implemented and tested in phase 3. Here we report the study protocol of phase 1 and 2.

Ethics and dissemination The study is registered with the Danish Data Protection Agency (19/22672). Approval of the project has been granted by the Regional Committees on Health Research Ethics for Southern Denmark (S-20192000–111). Findings will be published in suitable international journals and disseminated through conferences.

Strength and limitations of the study

► The proposed study will, through participatory design (PD), combine methods into the design and test of an innovative solution, seeking to improve patient and family outcomes in connection to their discharge from the emergency department (ED). This will provide insight into patient and family needs during their ED pathway.
► It is a key feature in the study to ensure user involvement from all stakeholders and sustainability of the developed solution, as it is drawn directly from patients', family members' and healthcare professionals' statements, experiences and ideas.
► The study includes family perspectives, which is limited in previous research from an ED perspective.
► Using PD could be time-consuming and might be a limitation, as it could be difficult to gather relevant stakeholders at the same time.

INTRODUCTION

When patients have an acute episode of symptoms or instability of a chronic disease, they often have feelings of fear and helplessness due to the uncertainty of the situation. This brings patients and their families to the emergency department (ED) in a vulnerable and distressed situation.[1] The care provided at the ED will influence the patient's and family members' experience of the current stay and influence their ability to understand and use health information for maintaining their health after discharge.[1–3] Family members rank supportive communication with nurses as vital to reduce stress and anxiety.[4] Emergency nursing care is administered by systematic guidelines based on, for example, Airway, Breathing, Circulation, Disability, Exposure (ABCDE) principles to support effective patient pathways and to identify specific patient needs, making it possible for nurses to respond rapidly and effectively.[5] The majority

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of patients with acute symptoms are initially cared for in a general ED or common acute medical and surgical emergency unit.[6] Many countries have this organisational structure and systematic approach to ensure fast, systematic and comprehensive assessment along with the improvement of patient flow.[7 8] The organisational structure has a positive effect on preventing overcrowding and is also a result of the reduced number of in-hospital beds.[9] Attention is often on organisational concerns, but there is a need for exploring patient-related aspects as well.

Acute nursing care is characterised by rapid and efficient treatments. This often results in short and fragmented encounters between patients and nurses.[2 10] Previous research on patient perspectives has shown that patients feel that ED nurses seem to lose interest in the patient's life situation after the most acute treatment has been initiated.[11] In line with this, a Danish National Survey revealed that 33% of patients did not experience that their family's perspective was considered important.[12] Furthermore, 30% of the patients participating in this survey reported that they were not involved in the decision-making process of their care.[12] These findings indicate that the international and national health standards for patient involvement are not met.[13 14] Healthcare professionals' acknowledgement of the family's role and inclusion in care decisions enable the family to improve the patient outcomes, but also ensure that family caregivers understand information and are able to coordinate care and manage practicalities.[15] A way to improve the quality of care would be to give patients and families a stronger voice. This could help identify their needs and the resources they use, to enable supportive care to be tailored.[16] To enable nurses to assess and partner with patients and families to meet their needs and tailor care during short nurse–patient interactions, a nurse-led intervention may be useful.[17] Previous research exploring ED patients' expected outcomes identified four main concerns: understanding diagnosis, symptom relief, reassurance and treatment plans.[6 18] However, the family perspective was not reported in these studies. ED nurses highlight family members as an important resource to obtain information, and needs more research.[19] Furthermore, research has identified numerous discharge interventions and strategies to prevent readmissions; however, these are primarily concerning elderly, frail patients and not inclusive of family members.[20–23] Sparse research has been conducted focussing on the diversity of ED patients and their families, highlighting the need for interventions on how to assess and tailor care.[24–26]

Objective

The overall aim of this study is to improve patient outcomes by nurse assessment and tailoring care for patients and family members discharged from the ED <24 hours.

Following research objectives will guide each phase:

1. To create knowledge about what patients, family members, and healthcare professionals do and what they say they do, in connection to patients discharged within 24 hours (phase 1a).
2. To assess the needs and preferences of patients and families admitted in the ED to gain an understanding of patients and family needs (phase 1b).
3. To understand how healthcare professionals in the ED perceive patients and family needs and preferences, and how they would accommodate these in their care (phase 1c).
4. To design and develop a solution to improve patient outcomes using focus group workshops (phase 2).

Methods

The overall research design and methodology for this study is participatory design (PD).[27] The Family System Theory[28] and the framework of Medical Research Council[29] for developing interventions in healthcare are used to guide the study.
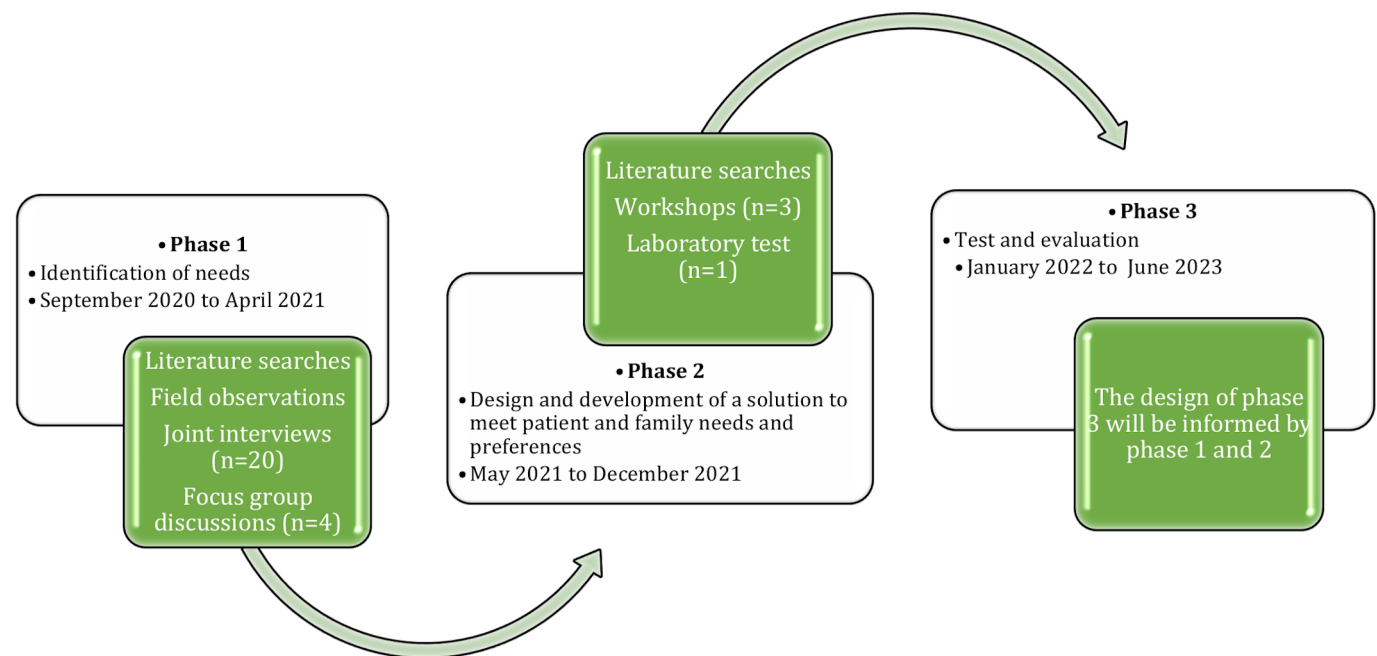
Study design

PD is chosen as research methodology as it includes the participants in the design phase and is relevant to use in research areas with limited knowledge.[27] PD is defined by making innovative solutions to problems in real life through a democratic stance and genuine participation of all relevant participants which represent future end-users of the field.[30] It enables the focus to be on future end-users in designing an intervention strategy that provides possibilities to improve patient outcomes in the ED. A PD process conducted in health science is typically performed in three interdependent phases[31] and is characterised by collective 'reflection-in-action' iterations. In phase 1, the focus is to identify user needs. In phase 2, a prototype as a solution to cover the identified needs is developed. Finally, the solution is implemented and tested in a clinical setting and its effect and success will be evaluated. Here we report on the study protocol for phase 1 and 2. As the three phases are interdependent, phase 1 will provide the information and inform phase 2 and so on. Therefore, phase 2 cannot be predesigned, wherefore an exploratory approach will be used as design.[27 32] With an explorative approach, patient outcomes are not defined in advance but will be identified by the patients and family members in the initial phase of the study. However, the main outcome must be focussed on the quality of care expressed by patients. A literature review exploring ED patients' outcomes and clinical interventions will be completed for each phase to ensure an understanding of current research to inform the study.[33]

To identify patient and family needs and preferences, field observational studies inspired by Spradley[34] will be obtained by the first author, followed by joint semi-structured interviews of patients and family members.[35] Focus groups of healthcare professionals will enable sustainable and an achievable solution to develop. An intervention plan developed from phase 1 will be constructed and relevant stakeholders and future end-users of the solution will be invited to participate in three workshops

Acute Care planning in Emergency departments (The ACE study): protocol of a participatory design study.

Figure 1 The estimated time frame and methods of the Danish study 'Acute Care planning in Emergency departments, (The ACE study)'.

to finalise the design. The workshops will be designed to focus on: (1) generation of ideas (2) workshop with the intention to create mock-ups for the creation of a final prototype and (3) a 'laboratory' workshop where this prototype is pretested in a clinical setting.[27] A 'laboratory' workshop is characterised as deliberately staged activities during which a controlled environment for exploration is created, and open collaboration between the participants is facilitated.[27]

The Medical Research Council[29] framework of developing complex interventions will be used to guide this study: (1) development (2) feasibility and (3) evaluation in line with the three phases of the study's research design, as illustrated in figure 1. The Medical Research Council argues that an intervention is complex when it contains several interacting components.[29] The current study will include a range of patients, families, healthcare professionals and organisational changes.

Theoretical framework

The theoretical framework is based on the Family Systems Theory[28] that care is provided holistically with patient and family as the unit of care. According to Wright and Leahey, family members could be spouses, partners, adult children, friends or others from the care-recipient's social network who care for the patient. Family Systems Theory aims to help families to achieve stability in their lives by focusing on their internal relationships, resources and capacity to adapt to new situations caused by illness.[28]

This framework guides the research process including sampling, designing intervention and research aims. After episodes of care in emergency, the family is the main carer and provider of support. Therefore, to improve patient outcomes, the family's inclusion is required to enable family information needs to be met.[11]

Setting

The study is carried out from September 2020 to June 2023, as shown in figure 1. Data will be collected from the ED at two hospital sites: (1) The Odense University Hospital (OUH), which is a 1000 bed university hospital, and covers all specialities and provides care for a population of 230 000 adults living in four municipalities. The ED seeing 69 000 annual attendees, mean age 45, treats 180 patients per day with a capacity of 42 beds and 30 examination rooms. On average, 32 patients are admitted to the hospital per day, and 50% are discharged within 24 hours.

(2) Department of Emergency Medicine, Hospital of Lillebaelt, Kolding. The Hospital of Kolding has the capacity of 320 beds. The ED seeing 50 000 annual attendees, mean age 45, receives 146 patients per day and has 58 beds and 5 trauma rooms beds capacity. The EDs are organised as they can control the allocation of the in-hospital beds at the rest of the hospital.

The Danish healthcare system is provided with open access and people do not need health insurance to be seen by a physician as it is a tax-funded welfare system.

Table 1 Patient features in phase 1 of the Danish study 'Acute Care planning in Emergency departments (The ACE study)'

Patients (n=20)	Specific attributes
Age	≥65 years of age/≤65 years of age
Sex	Equal male and female
Symptoms	Equal surgical/medical symptoms
Education level	Below/above secondary school
Function level	Receiving primary care/not receiving primary care
Social status	Living independently/living with someone

Acute patients are evaluated in person or by emergency calls by primary care physicians who act as gatekeepers before entering the ED. Denmark has a well-established and free of charge primary care, public pre-hospital emergency transport and treatment at public hospitals. When patients are discharged, they can get uncharged follow-up by their general practitioner, primary nursing care or in an outpatient clinic.

The study is affiliated with the Family Focused Healthcare Research Center (FaCe) at the University of Southern Denmark.[36]

Participants
Patients and family members
Inclusion criteria

Purposive sampling of patients: ≥18 years of age, Danish-speaking, discharged <24 hours with medical or surgical symptoms. Family members, invited by the patient, are included.

The target study population is shown in table 1.

Sampling strategy will ensure equally represented patients with first time visits among patients with multiple ED visits. Other collected variables: gender, age, civil status, educational level, length and frequency of stay, diagnosis, Charlsons comorbidity score and family relations.

Exclusion criteria

Cognitive impairment assessed by the nurses by using Glasgow coma scale added by individual clinical judgement according to be able to understand the terms of participating in a research study. Highest and lowest triage level according to Danish Emergence Process Triage.[37]

Healthcare professionals

Nurses, physicians and physiotherapist working at the ED>6 months will be included. Inclusion will be done purposively to enable a broad sample of healthcare professionals.

Other collected variables: gender, age, profession, years since graduation years of employment at the ED and educational level.

Collaborators and consultants

The participants in this category will be identified during the analysis of phase 1. It seems relevant to look into previous research, consulting experienced researchers within PD and looking into exciting interventions in healthcare, IT software engineers, design schools, communication advisors, sociologists, anthropologists and cross-sectoral partners.

Phase 1a: field observations
Research objective

To create knowledge about what patients, family members, and healthcare professionals do and what they say they do, in connection to patients discharged within 24 hours.

Method

Field observations will be conducted in both EDs (estimated n=10 days of 4 hours a day) to include relevant perspectives in the understanding of patient and family needs and preferences. We chose four to 6 hours as time frame for the field observations based on National standards stating that patients in the Danish EDs should receive a treatment plan within 4 hours.[38] All sample sizes in the study are based on scientific guidance of qualitative research.[39] Field observational studies are chosen as it has the strength to create direct knowledge about what participants do and what they say they do,[40] in connection to their treatment and care in the ED. Field observations are planned at different weekdays and times of the day to show the potential diversity. The duality of being a researcher, experienced nurse and employed at the department at the same time will be accessed as objectively as possible by using a template for documentation of field notes, inspired by Spradley.[34] Each day, field notes will be taken and transcribed immediately to secure correct recall.[34] The notes are expected to consist of descriptions, illustrations and short quotations. Approval from the management of the departments was obtained in February 2020. Data from field observations will actively be used to understand what the patients have experienced and inform the development of the interview guide.

The interviewer is an experienced emergency nurse with a Master's degree (12 years of emergency nursing). From previous research, she has experience doing intervention and qualitative research.[41 42] She is supervised by an experienced research team that is involved in every aspect of the project.

Phase 1b: interviews with patients and family members
Research objective

To assess the needs and preferences of patients and families admitted in the ED to gain an understanding of patients and family needs.

Method

Guided by a phenomenological hermeneutical framework, patients and family members from both EDs will be interviewed face-to-face or by telephone within the first week after their emergency visit (n=20). Recruitment of

patients and family members will occur during the observational study. Patients will be approached and provided with a plain language information sheet of the study and asked if they would be interested. Once patients are recruited, family members will be invited into the study. Using a purposive sampling technique will ensure balance across the different patient features from table 1.

Semi-structured family interviews will be conducted in person. The interview guide will begin by asking participants to share about their visit to emergency. The researcher will ask participants to elaborate on different aspects of their emergency visit from the observation data collected. Interviews will be conducted at a time and place convenient for the patient and family member. Interviewing patients and family members is aimed at identifying both their individual and common experienced needs and preferences. Interviews enable the participant's perspectives and experiences to be shared to gain an understanding of the experience.[43] A question example is: 'What have you talked about since discharge?' We will continue recruitment until thematic saturation is reached; the point at which no new themes are emerging.[39] This will include a minimum of 20 participants to secure maximal variation of the target group but will be continued if the thematic saturation is not reached within this sample size. We chose this sampling strategy as it is designed to ensure that a full range of themes is elicited within each group.

Phase 1c: focus group interviews with healthcare professionals

Research objective

To understand how healthcare professionals in the ED perceive patients and family needs and preferences, and how they would accommodate these in their care.

Method

Four focus groups will be conducted with approximately n=20 nurses and physicians equally from both sites. Focus groups are an effective way to produce group-level data, based on the interpretation, interaction and norms of social groups.[44] Participants are asked to discuss quotes from patients' and family members' interviews to understand healthcare professionals' perspectives and reactions to these quotes. The interactions between participants can lead to participants contributing spontaneous statements about the given

subject, and new ideas are created. The first author moderates the focus group together with one of the more experienced researchers from the research team. Observations of the non-verbal communication, the group-interaction and elaborating questions will be recorded as field notes.[44] Each focus group will consist of four to six participants.[45]

Analysis: phase 1a–c

Qualitative data from the joint interviews, focus group interviews and field observational studies will be synthesised and analysed in a phenomenological and hermeneutical framework. The hermeneutic approach allows us to gain an insight into the individual's lived experience and provides an interpretive perspective to explicate meanings and assumptions in the data by studying and interpreting narrative.[39]

To organise the process of the analysis, the steps from Malterud's[46] systematic text condensation (STC) will be used in NVivo12. First, we will capture a general impression of the data and extract preliminary themes. Second, the data will be allocated into meaningful units which is a text section that represents pieces of information about a research question. The meaningful units will be condensed and coded, and finally, findings will be synthesised. To ensure the trustworthiness and rigour of the analysis process, we will follow the standards for reporting qualitative research of O'Brien et al.[47]

The progressive process line in phase 1 is shown in figure 2.

Phase 2: design and development of a solution in a workshop process

The second phase is the actual development of a solution to improve patient outcomes by nurse assessment and improved tailored care to patients and family members, discharged from the ED <24 hours.

Research objective

To design and develop a solution to improve patient outcomes using focus group workshops (phase 2).

Method

A co-design framework will be used. The process of design and development of a solution will be affected by involving participants across all areas in workshops and

Acute Care planning in Emergency departments (The ACE study): protocol of a participatory design study.

Figure 2 Progressive process of phase 1.

in the laboratory workshops. This will enable discussion of needs, mutual learning and creativity, ensuring that the solution is innovative and user-focussed.[27] Initially, an idea-generating workshop will be conducted, followed by a mock-up workshop, creating a temporary proto-type of the solution. Workshops will consist of different participants representing different perspectives: patients, family members, various healthcare professionals, IT designers, innovation consultants, the research team among others. Collecting a broad variety of participants with different backgrounds, and perspectives will bring nuanced perspectives to the process and the ability to predict possible challenges with the prototype.[27 29] The workshops will be facilitated as a space for creativity and 'reflection-in-action' among participants. To facilitate this creative space, visualisation tools will be used, such as posters, personas and note paper or post-it notes.[30] The use of creative space allows participants and researchers to work as equal partners, bringing the iterative process into action. The results of the analysis will be presented for the invited participants by the research group to create direction. After the initial workshop, the research team will include the relevant stakeholders to proceed with the development of the solution. A possible solution will be informed by study 1 and the workshop process. Looking into previous research, intervention examples could be telehealth solutions, discharge follow-up or cross-sectoral collaboration.[48]

Finally, a 'laboratory' workshop pretesting the proto-type sees its feasibility and acceptability in practice.[30] This workshop will include a smaller number of participants as the aim is narrow, compared with the creative, innovative workshops.

The number of workshops and its attendees will depend on the process, but based on previous research using PD,[30 48] at least three workshops are estimated.

Analysis

Data from the workshops will be obtained as pictures, notes on posters, debriefing and recorded discussion during the workshops. The first author will transcribe and systematise the data into themes inspired by STC[46] and present them as a report. The report will be discussed by the research team and relevant collaborators for final adjustments before the test phase. The analysis and devel-opment of the model will be conducted iteratively in the following steps: plan, act, observe and reflect. This process is illustrated in figure 3.

The phase three evaluation will be developed from the most important patient reported outcomes identified in phase one and targeting the intervention in phase 2. The evaluation phase three will be published in a separate study protocol.

Data management plan, ethics and dissemination

Oral and informed consent will be obtained after providing plain language information.[49] Participation is voluntary, and it is possible, at any time, to withdraw from the study. The study is registered with the Danish Data Protection Agency (19/22672). Approval of the project is obtained from the Regional Committees on Health Research Ethics for Southern Denmark (S-20192000–111).

Data will be stored at Open Patient data Explorative Network (OPEN_938).[50] Findings will be published in suitable journals and disseminated through workshop and conferences.

Acute Care planning in Emergency departments (The ACE Study): Protocol of a participatory design study
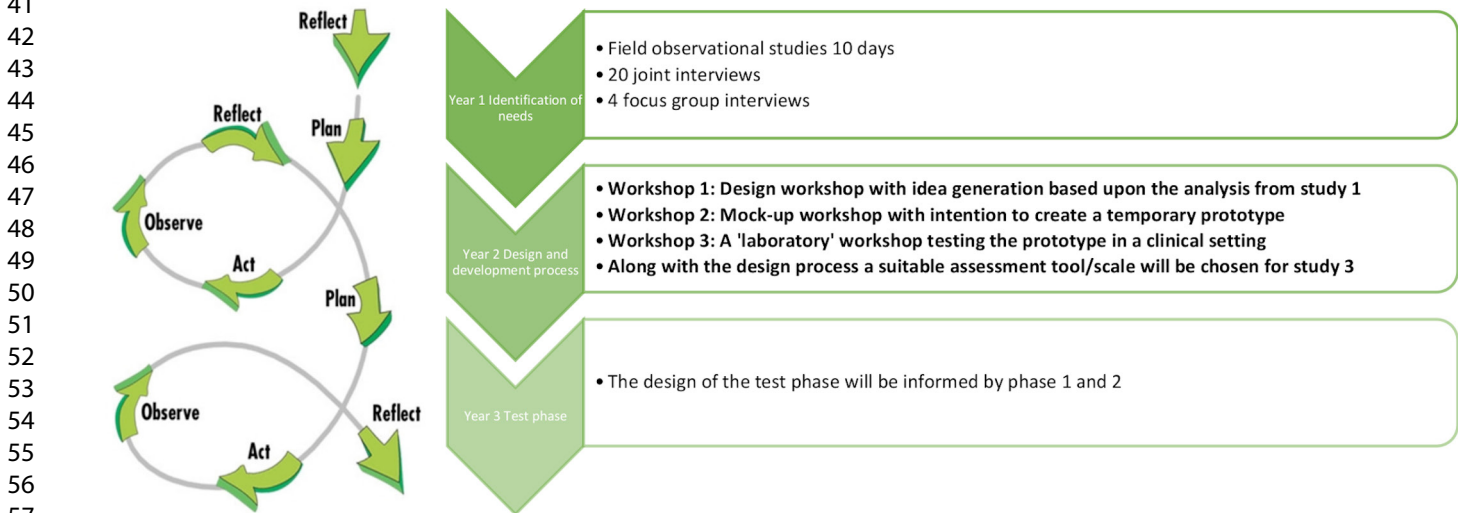

Figure 3 Iterations of phase 2: plan, act, observe and reflect.

Patient and public involvement

The local Patient Council at OUH was consulted in the early design phase of the study, and their perspectives were taken into account. The core element of the study is built around user involvement and its strengths and limitations will be elaborated on in the discussion section.

DISCUSSION

The use of a PD provides an innovative approach through the inclusion of users across the healthcare setting. PD and its methods are very productive research approaches, directing the design of the solution to support patients' needs and organisational changes in clinical practice.[31 51] The participatory approach ensures stakeholder involvement and sustainability of the designed solution as it is drawn directly from patients, family members and healthcare professionals. The data will provide a strong foundation to improve patient-valued outcomes and experiences of support. Co-production and focus on future end-users are increasingly applied in designing and improving healthcare, and have shown great potential to improve the quality and value of care.[30 48 52] In our study, we base the design and development on a qualitative foundation from the two main groups of end-users; patients'/family members' and healthcare professionals' descriptions of needs and preferences. By actively involving participants, the solution will be targeted at the main issues[8] in acute care and the likelihood of actually improving family-inclusive patient outcomes will increase. We consider participant interaction to be one of our study's main strengths, enabling a deeper understanding of emergency care. Collecting data at two different sites is considered a strength, as it will ensure the national generalisability of the findings.

As our protocol is based on co-production, it may be at risk of logistical and practical challenges by gathering different stakeholders. Challenges posed by engaging healthcare professionals in workshops relate to staff resources, and this must be addressed.[53] Phase 1 challenges will be to sample enough participants to be representative as the ED has a great diversity of patients with different ages, needs and diseases. Therefore, purposive sampling is chosen. Field observations may lead to irrelevant focus[34] and risk of the Hawthorne effect;[54] however, using an observation guide inspired by Spradley will ensure a systematic approach.[34] Although it is expected that both parties (patient and family members) will actively participate in joint interviews, the advantages and disadvantages must be addressed. The main disadvantage is the risk that one of the participants may be more conversational and may overrule the other one. However, joint interviews are chosen as the authors want to explore both perspectives and create a social interaction that could bring out their experiences in a nuanced way.[44] Involving participants actively in workshops and working in iterative processes will place demands regarding flexibility and willingness to change direction, if participants say so. This may be time-consuming and cost-intensive.

Summary

By focussing on co-production, this study is expected to contribute to an improved health outcome of acute illness and an improved understanding of how to support patients and family members to reach the ability to manage their situation after a short ED episode.

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REFERENCES

1 Hess EP, Grudzen CR, Thomson R, *et al*. Shared decision-making in the emergency department: respecting patient autonomy when seconds count. *Acad Emerg Med* 2015;22:856–64.
2 Elmqvist C, Frank C. Patients' strategies to deal with their situation at an emergency department. *Scand J Caring Sci* 2015;29:145–51.
3 Wåhlin I. Empowerment in critical care - a concept analysis. *Scand J Caring Sci* 2017;31:164–74.

4 Hsiao P-R, Redley B, Hsiao Y-C, *et al*. Family needs of critically ill patients in the emergency department. *Int Emerg Nurs* 2017;30:3–8.

5 Olgers TJ, Dijkstra RS, Drost-de Klerck AM, *et al*. The ABCDE primary assessment in the emergency department in medically ill patients: an observational pilot study. *Neth J Med* 2017;75:106–11.

6 Nielsen LM, Gregersen Østergaard L, Maribo T, *et al*. Returning to everyday life after discharge from a short-stay unit at the Emergency Department—a qualitative study of elderly patients' experiences. *Int J Qual Stud Health Well-being* 2019;14:1563428.

7 Scott I, Vaughan L, Bell D. Effectiveness of acute medical units in hospitals: a systematic review. *Int J Qual Health Care* 2009;21:397–407.

8 Stevens L, Fry M, Browne M, *et al*. Fast track patients' satisfaction, compliance and confidence with emergency department discharge planning. *Australas Emerg Care* 2019;22:87–91.

9 Christiansen T, Vrangbæk K. Hospital centralization and performance in Denmark-Ten years on. *Health Policy* 2018;122:321–8.

10 Frank C, Asp M, Dahlberg K. Patient participation in emergency care - a phenomenographic analysis of caregivers' conceptions. *J Clin Nurs* 2009;18:2555–62.

11 Forsgärde E-S, From Attebring M, Elmqvist C. Powerlessness: dissatisfied patients' and relatives' experience of their emergency department visit. *Int Emerg Nurs* 2016;25:32–6.

12 Kompetencecenter for Patientoplevelser, *Landsdækkende Undersøgelse AF Patientoplevelser*, 2017

13 Locock L, Boylan A-M, Snow R, *et al*. The power of symbolic capital in patient and public involvement in health research. *Health Expect* 2017;20:836–44.

14 INVOLVE, I.N. *What is public involvement in research? 2018* 2018 [cited 2019 18.02]; Available from: What is public involvement in research? 2018

15 Feinberg LF. Moving toward Person- and Family-Centered care. *Public Policy & Aging Report* 2014;24:97–101.

16 Muntlin A, Carlsson M, Gunningberg L. Barriers to change hindering quality improvement: the reality of emergency care. *J Emerg Nurs* 2010;36:317–23.

17 Mixon AS, Goggins K, Bell SP, *et al*. Preparedness for hospital discharge and prediction of readmission. *J Hosp Med* 2016;11:603–9.

18 Vaillancourt S, Seaton MB, Schull MJ, *et al*. Patients' Perspectives on Outcomes of Care After Discharge from the Emergency Department: A Qualitative Study. *Ann Emerg Med* 2017;70:648–58.

19 Hoffmann E, Olsen PR. Like an ACE up the sleeve: an interview study of nurses' experiences of the contact with relatives in a somatic emergency ward. *Scand J Caring Sci* 2018;32:1207–14.

20 Lavesen M, Ladelund S, Frederiksen AJ, *et al*. Nurse-initiated telephone follow-up on patients with chronic obstructive pulmonary disease improves patient empowerment, but cannot prevent readmissions. *Dan Med J* 2016;63.

21 Biese KJ, Busby-Whitehead J, Cai J, *et al*. Telephone follow-up for older adults discharged to home from the emergency department: a pragmatic randomized controlled trial. *J Am Geriatr Soc* 2018;66:452–8.

22 Hoek AE, Anker SCP, van Beeck EF, *et al*. Patient discharge instructions in the emergency department and their effects on comprehension and recall of discharge instructions: a systematic review and meta-analysis. *Ann Emerg Med* 2020;75:435–44.

23 Rosted E, Poulsen I, Hendriksen C, *et al*. Testing a two step nursing intervention focused on decreasing rehospitalizations and nursing home admission post discharge from acute care. *Geriatr Nurs* 2013;34:477–85.

24 Flynn D, Knoedler MA, Hess EP, *et al*. Engaging patients in health care decisions in the emergency department through shared decision-making: a systematic review. *Acad Emerg Med* 2012;19:959–67.

25 Melnick ER, Probst MA, Schoenfeld E, *et al*. Development and testing of shared decision making interventions for use in emergency care: a research agenda. *Acad Emerg Med* 2016;23:1346–53.

26 Lisby M, Klingenberg M, Ahrensberg JM, *et al*. Clinical impact of a comprehensive nurse-led discharge intervention on patients being discharged home from an acute medical unit: randomised controlled trial. *Int J Nurs Stud* 2019;100:103411.

27 Simonsen J, Robertson T. *Routledge international Handbook of participatory design*. Routledge, 2012.

28 Wright, Leahey M. *Nurses and families a guide to family Assesment and intervention*. 6th ed. F.A. Davis Company, 2013.

29 Craig P*et al*. *Medical Research Council complex interventions guidance*, 2008.

30 Jensen CM, Overgaard S, Wiil UK, *et al*. Bridging the gap: a user-driven study on new ways to support self-care and empowerment for patients with hip fracture. *SAGE Open Med* 2018;6:205031211879912.

31 Clemensen J, Rothmann MJ, Smith AC, *et al*. Participatory design methods in telemedicine research. *J Telemed Telecare* 2017;23:780–5.

32 Clemensen J, Larsen SB, Kyng M, *et al*. Participatory design in health sciences: using cooperative experimental methods in developing health services and computer technology. *Qual Health Res* 2007;17:122–30.

33 Coster S, Watkins M, Norman IJ. What is the impact of professional nursing on patients' outcomes globally? an overview of research evidence. *Int J Nurs Stud* 2018;78:76–83.

34 Spradley J. *Participant observation*. USA: Waveland Press, 1990.

35 Voltelen B, Konradsen H, Østergaard B. Ethical considerations when conducting joint interviews with close relatives or family: an integrative review. *Scand J Caring Sci* 2018;32:515–26.

36 Family Focused Healthcare Research Center. 2020 09.03.2020 [cited 2020 09.03]; Available from. Available: https://www.sdu.dk/en/om_sdu/institutter_centre/klinisk_institut/forskning/forskningsenheder/face

37 DEPT. *User Manuel Danish Emergency Process Triage - DEPT*. Available: http://deptriage.dk/brugervejledning/

38 Sundhedsstyrelsen, Danske Regioner, and Sundheds OG Ældreministeriet, de danske akutmodtagelser. Statusrapport 2016, 2017

39 Moser A, Korstjens I. Series: practical guidance to qualitative research. Part 3: sampling, data collection and analysis. *Eur J Gen Pract* 2018;24:9–18.

40 Green J, Thorogood N. *Qualitative methods for health research*. 3rd ed. Sage, 2014.

41 Østervang C. Patient Rounds With Video-Consulted Relatives-Qualitative Study on Possibilities and Barriers From the Perspective of Healthcare Providers.pdf>, 2019

42 Vestergaard LV, Østervang C, Danbjørg DB, *et al*. Video-Based patient rounds for caregivers of patients with cancer. *Oncol Nurs Forum* 2019;46:485–92.

43 Kvale S, Brinkmann S. *Interview: introduktion til et håndværk*. Kbh: Hans Reitzel, 2009.

44 Halkier B. *Fokusgrupper, in Kvalitative metoder: en grundbog*. København: Hans Reitzel, 2010.

45 Coyne E, Grafton E, Reid A. Strategies to successfully recruit and engage clinical nurses as participants in qualitative clinical research. *Contemp Nurse* 2016;52:669–76.

46 Malterud K. Systematic text condensation: a strategy for qualitative analysis. *Scand J Public Health* 2012;40:795–805.

47 O'Brien BC, Harris IB, Beckman TJ, *et al*. Standards for reporting qualitative research: a synthesis of recommendations. *Acad Med* 2014;89:1245–51.

48 Nielsen C, Agerskov H, Bistrup C, *et al*. User involvement in the development of a telehealth solution to improve the kidney transplantation process: a participatory design study. *Health Informatics J* 2020;26:1237–52.

49 Sykepleiernes Samarbeid i Norden Northern Nurses´ Federation, *Ethical guidelines for nursing research in the Nordic countries*, 2003

50 OPEN. *Open Patient data Explorative Network Clinical Institute University of Southern Denmark*, 2020. Available: https://www.sdu.dk/da/ki/open

51 Joshi SG, Bratteteig T. Designing for prolonged mastery. on involving old people in participatory design. *Scand J Inf Syst* 2016;28.

52 Trettin B, Feldman SR, Andersen F, *et al*. A changed life: the life experiences of patients with psoriasis receiving biological treatment. *Br J Dermatol* 2020;183:516–23.

53 Danbjørg DB, Wagner L, Kristensen BR, *et al*. Intervention among new parents followed up by an interview study exploring their experiences of telemedicine after early postnatal discharge. *Midwifery* 2015;31:574–81.

54 Mostafazadeh-Bora M. The Hawthorne effect in observational studies: threat or opportunity? *Infect Control Hosp Epidemiol* 2020;1.

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the inter view or focus group?	
Duration	21	What was the duration of the inter views or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

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